University of Alberta

The Quality of Life of Adult Asthmatics

by

Katharina Ann Van Veen

A Thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Quality of Life of Adult Asthmatics**, submitted by **Katharina Ann Van Veen** in partial fulfillment of the requirements for the degree of **Master of Nursing**.

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Abstract

The purpose of this study was to examine the quality of life of a group of adult asthmatics from a community setting. An exploratory, nonexperimental research design was used in a sample of fifty-six subjects to explore the relationships between gender, objective and subjective asthma severity on quality of life. The clinical characteristics of this sample were congruent with a well controlled mild category of asthma. Major findings included that the quality of life of adult asthmatics in this sample was relatively high. There were no differences between gender on quality of life. There appears to be a relationship between how individuals perceive their disease severity and quality of life. Nursing implications include the importance of assessing individuals' perception of asthma severity. Given the small sample size and non-random sampling technique, replication of this study is required.

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CHAPTER ONE

Introduction

Asthma is a chronic respiratory disease that affects four to five percent of the adult population (Halfon & Newacheck, 1993). In the past several decades, Alberta and Saskatchewan have reported the highest mortality rates for asthma in the country (Mao, Semenciw, Morrison, MacWilliam, Davies & Wigle, 1987; Svenson, Woodhead & Platt, 1993; Wilkins & Mao, 1993). There is a growing interest in using quality of life measures to assess the impact of interventions on adults with asthma (Rose & Weiss, 1996; Gruffydd-Jones, 1997).

Research in the area of quality of life has developed rapidly over the past several years. The well-being of individuals has been recognized as equally as important as physical treatment and cure (de Haes & van Knippenberg, 1985). Individuals are becoming more involved in decisions regarding their own health which includes consideration for their quality of life. Medical progress and the increased cost of healthcare has also prompted policy-makers to consider quality of life when evaluating expensive medications, prolonged treatments and health care interventions (Hadorn, 1991). The development of quality of life research will enhance the ability of individuals to make their own decisions regarding their health care. As health care professionals, nurses have a responsibility to be involved and contribute to this area of research as quality of life affects patient care.

Although the quality of life of an individual can be measured through objective criteria, e.g. job status or income, it is how the individual perceives their own life that ultimately defines quality of life (Cella, 1992; Ferrans, 1990). Quality of life tools have

been developed to provide a "quantification of the impact of disease on a patient's life and perceived well-being in a formal and standardized manner" (Jones, 1991, p. 677). Several disease-specific quality of life tools have been developed for respiratory disease (Ferrans & Powers, 1992; Maille, Koning, Zwinderman, Willems, Dijkman & Kaptein, 1997) and specifically for asthma (Hyland, 1991; Juniper, Guyatt, Ferrie & Griffith, 1993; Marks, Dunn & Woolcock, 1992).

There have been several studies conducted regarding asthma and quality of life. The majority of these studies have been medication trials that have utilized quality of life as an outcome measure. Decreased asthma severity has been correlated with improved quality of life in eight of nine studies (Apter et al. 1996; Hyland, Kenyon & Jacobs, 1994; Jones et al. 1994; Juniper, Johnston et al. 1995; Mahajan, Okamoto, Schaberg, Kellerman & Schoenwetter, 1996; Mao, Semenciw et al. 1987; Marin, Carrizo, Garcia & Ejea, 1996; Okamoto, Noonan, Deboisblanc, & Kellerman, 1996; Rutten-van Molken et al. 1995). Malo and colleagues (1993) found in a study of occupational asthmatic adults, that subjects with more severe asthma had a decrease quality of life. They recommended that further research comparing asthma severity and quality of life is needed to determine the magnitude of differences between subjects (Malo et al. 1993).

Gender differences on quality of life scores, beyond baseline characteristics, has had only minimal attention in the published literature (Malo et al. 1993). Although asthma severity has been associated with quality of life, gender has not been clearly recognized as an important variable to study. The various domains inherent in quality of life tools has not been clearly described or explored in relationship to gender or disease severity.

Purpose of Study

The purpose of this study was to gain information on the quality of life of adult asthmatics. This study described the quality of life of adult asthmatics using two disease specific quality of life measurement tools. Gender and disease severity was also explored in relationship to the quality of life of adult asthmatics. The specific research questions addressed were:

1) What is the quality of life of adults with asthma who have been referred to a pulmonary specialist in a Canadian out-patient setting?

2) Are there differences between women and men with asthma and quality of life?

3) Do asthmatics with low objective asthma severity compared to those with high objective asthma severity differ in quality of life?

4) Do asthmatics with low subjective asthma severity compared to those with high subjective asthma severity differ in quality of life?

Significance of the Study

The measurement of quality of life is important to clinical practice to facilitate communication, identify aspects of an individual's life that are the greatest concern and to plan and evaluate individualized interventions based on this information. It is important to study the concept of quality of life from a nursing perspective. Quality of life facilitates the provision of patient-centered care, based on the individual patient's values (Ferrans & Powers, 1992). The nature of nursing is such that many of the interventions and anticipated outcomes impact the quality of life of individuals (Harrison, Juniper & Mitchell-DiCenso, 1996). Quality of life can be used as an outcome measure when

evaluating nursing practice therefore it is imperative that nursing research is conducted in this area.

The research was designed to explore the quality of life of adult asthmatics. Information from this study can be used to describe the characteristics of adult asthmatics and their quality of life. The results of this study will help to clarify the relationship between gender, disease severity and quality of life. These findings will contribute to knowledge regarding the specific disease asthma. Finally, this study will also contribute to the growing body of knowledge in the nursing literature regarding quality of life.

Summary

The purpose of this study and the research questions have been established in this first chapter. The significance of quality of life and asthma, as it pertains to Nursing, has been explicated. Chapter 2 contains a review of the literature on quality of life, asthma and relevant research done in this area. The study design and methodology are presented in Chapter 3. The results of the study are documented in Chapter 4. Discussion, limitations, recommendations for further research and implications for nursing for practice are presented in Chapter 5.

CHAPTER TWO

Literature Review

The literature was examined for information on asthma and quality of life. The literature review is presented as follows: first, a definition of asthma will be presented. Secondly, the concept of quality of life will be discussed including historical background, conceptual and operational definitions. Thirdly, research regarding quality of life and asthma will be discussed in relationship to gender and disease severity.

Asthma

Asthma is a chronic inflammatory disorder of the airways. In asthma there is a narrowing of the airways, or bronchi, which causes a greater effort to draw air into the lungs and to expel this air. An asthmatic's airways are sensitive or hyperresponsive, and when irritated, airflow is limited and exacerbation's (or attacks) occur causing coughing, shortness of breath and difficulty breathing. These symptoms are highly variable both in occurrence and severity. Symptoms can be intermittent, only occurring at certain times of the year, or persistent, occurring two or three times a week (National Institutes of Health, 1995). Generally asthma severity is classified as mild, moderate or severe based on symptoms, clinical signs and pulmonary function tests. There is no universally accepted gold standard that measures and classifies asthma severity (Enright, Lebowitz & Crockroft, 1994; Wahlgren, Hovell, Matt, Meltzer, Zakarian & Meltzer, 1997). The Asthma Committee, of the Canadian Thoracic Society, have developed Canadian Consensus Guidelines for consistency in defining asthma severity and for the treatment of asthma. Asthma is defined as "a disorder of the airways characterized by paroxysmal or

persistent symptoms (dyspnea, chest tightness, wheeze and cough), with variable airflow limitation and airway hyperresponsiveness to a variety of stimuli" (Ernst, Fitzgerald & Spier, 1996, p.89).

The exact cause of asthma is complex and can be considered an interaction between genetics and environmental factors (Hopp & Townley, 1990). A strong family history of asthma increases the likelihood that an individual may develop asthma, but environmental factors can also affect the development of asthma in some people. Acute exacerbation's of asthma are often triggered by environmental allergens that can be found both indoors and outdoors, at work and at home. Air pollution, dusts, molds, fungi, cigarette smoke, and animals can all trigger an asthma attack. Emotions and personal stress may also affect asthma patients (Lane, 1996). The primary goal in the control of asthma symptoms is to obtain the best results possible for an individual with the fewest symptoms, the least interference with daily activities, and with the minimal amount of medication (Ernst, Fitzgerald & Spier, 1996).

Non-invasive pulmonary function tests are used to diagnosis asthma, determine severity and manage treatment. Measuring devices, called spirometers, record the rate and the flow of air exhaled. The forced vital capacity (FVC) is the amount of air that can be forcefully expelled from a maximally inflated lung. Force expiratory volume in 1 second (FEV_1) is the volume of air expelled during the first second of the FVC. Values are expressed as a percentage of the value expected for someone of the same gender, age and height. The rate of the forced air exhaled rises quickly (peak flow) and then declines slowly until all the air is expelled. In asthma patients, narrowed airways cause resistance,

therefore, not as much air can be expelled in 1 second and the FEV_1 will be reduced (Mosby, 1992; West, 1992). With asthmatic patients, 15 minutes after the administration of a $beta_2$-agonist (a short acting inhaled medication) the FEV_1 should increase as the airways expand in response to the medication administered. A 12% or greater improvement in FEV_1 (at least 180 ml) is considered significant for a diagnosis of asthma (Ernst, Fitzgerald & Spier, 1996). The concept quality of life will now be presented.

Quality of Life

Aristotle, whose discussions regarding the pursuit of happiness and what constitutes the good life, is considered by some to be the first reference to quality of life (Adler, 1978; Ferrans, 1996; Kleinpell, 1991; Molzahn, 1990; Zhan, 1992). The quality of life of an individual was recognized early in this century by the World Health Organization in their efforts to define health as more than the absence of disease and infirmity (WHO, 1947). The concept of quality of life was developed following the second World War to emphasize the good life, which required more than just material resources. In a 1964 speech by Lyndon Johnson, a former American president, the phrase 'quality of life' was first used and has subsequently been referenced in a multitude of situations (Campbell, 1981; McCall, 1975). From these early beginnings, the term quality of life has proliferated, but a lack of agreement on how to define this concept has remained.

Conceptual Definition

The nature of the concept 'quality of life' is abstract and cannot be directly observed. Abstract concepts must be identified by their attributes and characteristics, which when well developed are easily recognized as defining that concept (Morse,

Hupcey, Mitcham & Lenz, 1996). QOL has been described as polymorphous when, in a review of over 250 QOL articles, it was found that only a few articles using the term quality of life actually defined the concept (van Dam, Somers & van Beek-Couzjin, 1981). Although efforts have been made to define quality of life multiple definitions exist, and to date the concept has not been universally defined (Kleinpell, 1991; Meeberg, 1993; Oleson, 1990; Zhan, 1992). This lack of a universal definition can lead to inconsistencies in the interpretation of quality of life and how it is measured (Ferrans & Powers, 1985). Clarity in defining the concept is critical because differences in meaning can result in substantial differences in outcomes for both research and practice.

To define quality of life, it is important to first examine the etymology of the concept. Quality of life is not found in the dictionary as a single term, therefore, quality and life, will be examined separately. Webster's (1986) dictionary has 21 different definitions for the term life which include: 1) an animate being: the quality that distinguishes a vital and functioning being from a dead body or purely chemical being; 2) the course of existence: the sequence of physical and mental experience that make up the existence of an individual; and 3) the earthly state of human existence as distinguished from the spiritual state after death. Life refers to the capacity for growth, functional activity and continual change until death, living things and their activities are life (Oxford, 1993). It is clear from these definitions that life pertains to living beings, and although plants are alive, only animals and humans have life (Meeberg, 1993). Molzahn (1990) states although life is a complex concept, it is one that most individuals seem to understand. The word quality comes from the Latin origin of *qualis*, meaning 'of what

kind' (Webster, 1986). In contrast to the term life, Webster's has only 8 definitions for the word quality which include: 1) peculiar and essential character; 2) degree of excellence, 3) a special or distinguishing attribute. Quality refers to general excellence (Oxford, 1993). When quality is combined with life, there is the notion that quality is not only an essential feature of life, but also a distinguishing one. Quality can also imply a comparison, as there are varying degrees of excellence in life. McCall (1975) suggests that quality of life is a special or distinguishing attribute in a non-evaluative sense.

Much debate has occurred in the literature regarding what should be included as essential components in a definition of quality of life (QOL) (Ferrans, 1990; McCauley & Bremer, 1991). Similar concepts such as well-being, worth of life, happiness, satisfaction, and physical functioning have been included in definitions of quality of life. QOL definitions can also include either subjective criteria, objective criteria or both, and can have either a unidimensional or multidimensional focus. The following section will address the various components of quality of life definitions.

Objective and Subjective Definitions

QOL can be defined objectively using external conditions or descriptions of life-style. These objective measures or social indicators include socio-economic status, employment, education, living conditions, health, and marital status (McCauley & Bremer, 1991; Oberman, Wayne, Kouchoukos, Charles, Russell & Rogers, 1982; Stormberg, 1988). Campbell, Converse and Rodgers (1976) argue that although these indicators represent the individual's life condition they do not measure that individual's actual life experiences. The use of only objective indicators may contribute little to understanding an

individual's quality of life experience, and what is ultimately chosen to be measured may be based on a researchers own values and priorities which can result in bias (Holmes, 1989; McCauley & Bremer, 1991; Najman & Levine, 1981). This has been supported in the findings of Pearlman & Uhlmann's (1988) study where objective physicians' ratings of patient's QOL correlated weakly ($r = .30$) with the subjective patients' ratings on the same scale.

To assist medical practitioners, Shaw (1977) proposed an equation to provide an objective and quantitative manner in which to identify factors which affect quality of life. The equation is meant to focus on quality of life factors that physicians may otherwise not consider. Eleven years later, Shaw (1988) continues to clarify the intent of the equation as a means to assist in the analysis of situations where an individual is incompetent to make a QOL decision independently (i.e. infants, the comatose, or otherwise mentally incompetent). Shaw argues that decisions regarding medical treatment must be made and this equation simply assists in considering not only an individual's physical, intellectual and social capacities, and the burden of suffering, but also the resources realistically and reasonably available to help achieve a life 'worth living'.

QOL can also be defined in a subjective manner, where the individual evaluates their own QOL. Cella (1992) states that QOL can only be understood from the patient's perspective. The underlying thought processes of an individual mediates their perceptions, and therefore, their quality of life. Cultural, ethical, religious and other personal values can influence the perceptions and meaning of QOL (Zhan, 1992).

Happiness and satisfaction are two concepts that have been related to subjective QOL, but should not be considered synonyms with QOL (Ferrans, 1990; McCauley & Bremer, 1991). Happiness can be considered a short-term feeling or transitory affective state, whereas satisfaction is a judgment or cognitive evaluation of life's conditions. Life satisfaction is responsive to change, can be influenced by external conditions and is considered to more closely relate to the concept QOL (Campbell, Converse & Rodgers, 1976; Zhan, 1992). Life satisfaction has been used to determine convergent validity for a quality of life measurement tool (Ferrans & Powers, 1985).

An individual's perception of illness may be affected by how they feel and think, regardless of the observable objective criteria in which their illness is measured. Subjective issues related to defining QOL include: that "good or bad" QOL may mean different things to different people; that validity becomes more difficult to assess when measuring subjective verses objective QOL; and that it is difficult to collect subjective data when patients are unable to communicate verbally (Ferrans, 1990; Campbell, Converse & Rodgers, 1976). These issues must be considered when defining quality of life.

Definitions that include the use of both objective and subjective indicators to define and measure QOL can be found in the literature (Campbell, Converse & Rodgers, 1976; McCall, 1975). However, Ferrans (1990) states "objective indicators are important as measures of QOL, but should be interpreted as supplementary to subjective indicators, which measure QOL more directly" (p. 252).

Dimensions

Another issue when defining QOL is the identification of factors that assist in defining the concept. Some researchers have devised a single-item scale to measure the overall quality of life of an individual (Bernheim & Buyse, 1984). Molzahn (1990) suggests that an overall total score is appropriate to measure QOL and that a single rating on a scale or continuum, from very low to very high should be considered. Cella (1992) suggests that this should be considered a simplistic notion and a unidimentional scale is not a reasonable estimate of overall quality of life.

Multidimensionality refers to the broad range of factors or domains that when combined define the global construct of quality of life. Cella (1994) argues that although QOL is multidimensional, there is less agreement as to the specific nature of these dimensions. The author further states that psychometric data that might help to determine the underlying dimensions of QOL tools are rarely reported. Researchers in the social sciences have done extensive work in developing the domains associated with QOL (Andrews & Withley, 1976; Campbell, Converse, & Rodgers, 1976; Flanagan, 1982). Flanagan (1982) used an empirical approach, the critical incident technique, to define the main determinants of QOL which were 15 components important to an individual's QOL. Dimensions of QOL can also include physical, functional, emotional and social well-being (Cella, 1994).

Zhan (1992) defines QOL as the degree to which a person's life experiences are satisfying. The concept is both multi-dimensional and context-related: one's personal background, social situation, culture, environment and age influence a person's

perceptions of meaning and quality of life. Tartar, Erb, Biller, Switala and van Thiel (1988) have conceptualized QOL as a multi-faceted construct that encompasses the individuals' behavioral and cognitive capacities, emotional well-being, and abilities requiring the performance of domestic, vocational and social roles.

There is no universal definition or gold standard in which to define and measure QOL (Spritzer, 1987). Ultimately, how individual researchers choose to define quality of life depends on their particular ideology and on the instruments they use to operationalize the concept in any given clinical or research setting (Edlund & Tangredi, 1985; Harrison, Juniper & Mitchell-DiCenso, 1996; Ferrans, 1990; Kleinpell, 1991; Oleson, 1990).

Operationalization of the Concept

The broad nature of QOL presents a challenge to the researcher in the selection of an instrument, or instruments, to measure the concept when beginning a research project. When choosing an instrument in which to operationally define QOL, the researcher(s) should ensure that the entire construct is represented and that one or several instruments may be needed (Ferrans, 1990; Grant, Padilla, Ferrel & Rhiner, 1990; Jalowiec, 1990). Consideration must also be given to the conceptual viewpoint taken by the researcher. The distinction between what quality of life *is* from what *contributes to* quality of life needs to be determined (Harrison, Juniper, Mitchell-DiCenso, 1996; Stewart, 1992). Hyland, Finnis and Irvine (1991) suggest that the purpose for QOL tools is to meet either an economic or medical objective. Economically, the cost of a treatment is considered in relationship to the QOL of an individual, or medically, the outcome of clinical interventions is considered in relationship to the overall benefit to a patient. Both

objectives are related to outcomes and are measured through the use of QOL tools. Measuring QOL as a clinical outcome has become increasingly important in clinical trials (Guyatt, Veldhyzen van Zanten, Feeny & Patrick, 1989).

The multiple dimensions of QOL suggest that multiple perspectives and tools, are required to measure the QOL of individuals. Jalowiec (1990) outlines a variety of advantages and disadvantages to using multiple measure to assess QOL. Advantages include the ability to assess a wider range of dimensions affecting QOL, including subjective and objective indicators; greater flexibility in conceptualizing the concept; and the triangulation of measurement approaches will increase the psychometric properties of the instruments used. A comprehensive assessment of a patient's QOL will provide increased insight into which factors are being affected by the illness and which treatment regimes aid or distract from their QOL. Disadvantages of using more than one tool includes the increased time and energy required by the subjects to complete the questionnaires. The practical costs of utilizing several tools, including the complex statistical analysis that will be required on the part of the researchers, should also be considered.

The use of a single tool in which to measure QOL addresses the disadvantages of using multiple tools. Although the length of the instrument may be increased, the administration of one questionnaire, the coding and the data analysis will be simplified (Grant, Padilla, Ferrell & Rhiner, 1990). In the selection of an instrument, consideration of the psychometric properties of that instrument is always necessary. Studies that test the

psychometric properties of QOL tools contribute to the advancement of a single definition of QOL.

Generic vs. Specific Instruments

There are two types of instruments for measuring quality of life. Generic instruments have been used to identify selected dimensions of QOL and include: The Sickness Impact Profile, the Psychological General Well-Being Scale, and the Nottingham Health Profile (Hyland, Finnis & Irvine, 1991; Kinney, 1995). There are also disease-specific tools that focus on dimensions important to a specific health problem such as asthma (Hyland, Finnis & Irvine, 1991; Ferrans & Powers, 1992; Juniper, Guyatt, Ferrie, Griffith, 1993).

Jones (1995) identifies the need for disease specific measurement tools when studying the QOL of specific populations. Pertinent aspects of quality of life related to a particular disease are regarded as being more sensitive to disease or treatment related changes in QOL than are found in general health status instruments (Mahajan, Okamoto, Schaberg, Kellerman & Schoenwetter, 1997).

In summary, the definition of QOL is dependent on the tools utilized. Consensus in the literature suggests that the use of a single, multi-dimensional, disease specific tool is considered the most appropriate when measuring quality of life in specific populations. Research related to asthma and quality of life will now be presented.

Quality of Life and Asthma

Asthma medication trials have generally focused on the improvement of symptoms, but little recognition has been given to whether the patient actually feels better and can

function better physically, socially and emotionally in their everyday lives (Juniper, Guyatt, Ferrie & Griffith, 1993). This is especially true with asthmatic patients who may have improved pulmonary functioning with oral corticosteriods, but long term use of these drugs can have a profound effect on their quality of life e.g. Cushing's syndrome, peptic ulcers and hypertension (Okamoto, Noonan, deBoisblanc & Kellerman, 1996). Recent clinical trials that have studied the effectiveness of asthma medications have employed quality of life questionnaires when determining outcomes. The following section summarizes research studies that have utilized QOL as an outcome measure in medication clinical trials. The variables disease severity and gender will be the focus of this summary.

To date, the majority of research studies on asthma and quality of life have focused on the effects of various asthma medications. In an early research study, no relationship was found between the inhaled steroid medication, beclomethasone diproprionate and the quality of life of patients with asthma (van Schayck, Dompeling, et al. 1995; van Schayck, Rutten-van Molken et al. 1992). Quality of life was measured using the generic tools, Inventory of Subjective Health (ISH) and a Dutch version of the Nottingham Health Profile (NHP). At baseline, the subject population was noted to have a significant decreased QOL when compared to the general population. Results of this four year study were published after year two and at the end of year four. Although the researchers found that the asthma medication significantly improved lung function and temporarily decreased the severity of symptoms, this was not reflected in an improvement in QOL scores. Decline in FEV_1 values showed no correlation with QOL scores. The researchers concluded that an explanation for these findings may be due to the generic QOL tools

selected. Disease specific QOL tools, which might have been more sensitive to subtle changes in QOL, were not available at the start of their study. The researchers also suggested that the length of the study may have contributed to the inability to detect QOL changes as patients learned to live with their disease.

Since this early work, a relationship has been found between disease severity and within subject changes on quality of life (Apter et al. 1996; Jones et al. 1994; Juniper, Johnston et al. 1995 ; Mahajan et al. 1997; Malo, Cartier et al. 1996; Marin, Carrizo, Garcia & Ejea, 1996; Okamoto, Noonan, DeBoisblanc & Kellerman, 1996). The use of nedocromil sodium (NS), an oral asthma medication was found to decrease asthma severity and improve quality of life (Jones et al. 1994; Marin, Carrizo, Garcia & Ejea, 1996). The disease-specific tools, the St. George's Respiratory Questionnaire and the Asthma Quality of Life Questionnaire (AQLQ), were used to measure QOL in these studies.

The use of fluticasone propionate, an inhaled steroid medication, has also been found to contribute to improvement in asthma control and quality of life (Mahajan et al. 1997; Okamoto, Noonan, DeBoisblanc & Kellerman, 1996). Quality of life was measured using the Medical Outcomes Study Short Form-36 (SF-36), and the disease specific, Living With Asthma Questionnaire (LWAQ). The baseline measurement of subject's QOL was similar using both tools and both tools found improved QOL scores following medication treatment.

The disease specific quality of life tool, the AQLQ, was used to compare two inhaled asthma medications (Juniper, Johnston, et al. 1995). Findings included that the

QOL for mild to moderate asthmatics is better, both overall and for individual domains, when patients take salmeterol rather than salbutamol or a placebo. Juniper and colleagues (1995) state that when QOL is measured using a disease specific tool, the physical, emotional and social benefits of the medication used can be considered. Hyland, Kenyon & Jacobs (1994) in a study of the drug salmeterol, found that the QOL mean score on the Living With Asthma Questionnaire was positively correlated with medication usage. The scores from the domains sport, sleep, and work on the LWAQ demonstrated higher correlation's with medication usage than the mean score of the overall tool. The authors in both of these studies concluded that not only should QOL measures be included in medication trials, individual domain scores on QOL tools should also be taken into consideration.

Two research studies have identified improved QOL of asthmatics based on education programs (Boulet, Boutin, Cote Leblanc & Laviolette, 1995; Ringsberg, Wiklund & Wilhelmsen, 1990). Subjects in both studies were divided into two groups, those who received an asthma education program and those who did not receive the program. The Nottingham Health Profile, the Mood Adjective check list and a modified version of a QOL questionnaire for severe heart failure were utilized by Ringsberg, Wiklund and Wilhelmsen (1990). Boulet and colleagues (1995) utilized the AQLQ and chart reviews were done for one year before and after the education program. These reviews included emergency room visits, hospitalizations and absenteeism from work or school. It was noted that young women with a short duration of asthma had improved QOL scores. The researchers concluded that statistically significant changes in overall

AQLQ scores are quite difficult to obtain, especially if asthma is well controlled. They suggested that there may be more marked improvement in QOL for more unstable, severe asthmatics and education programs.

Malo and colleagues (1993) conducted a research study that described the QOL between two groups of adult asthmatics with occupational asthma. Quality of life was measured utilizing the AQLQ (Juniper, Guyatt, Ferrie & Griffith, 1993) as a discriminative instrument. Adult subjects with occupational asthma were paired for disease severity with a control group of non-occupational asthma subjects. Those with occupational asthma had a lower quality of life than the control group. There were no statistically significant differences in scores between men ($\underline{M}$ = 2.8) and women ($\underline{M}$ = 2.5). The researchers identified the need to further study groups of asthmatic patients to determine the magnitude of differences between subjects.

Gibson, Talbot and Toneguzzi (1995) conducted a cross-sectional, analytic survey on the self-management and autonomy of adult asthmatics related to QOL. Subjects were divided into two groups based on asthma severity. The AQLQ and an asthma autonomy questionnaire were mailed to subjects. The mean difference in overall AQLQ scores was .76 indicating that severe asthmatics had a significant decrease in quality of life. There were no statistically significant differences reported for gender. The researchers found no correlation between QOL and the autonomy of adult asthmatics. These results could not support their hypothesis that adult asthmatic subjects with high self-management autonomy have an improved QOL.

In the above studies, asthma severity has been defined in a variety of ways. Mild to moderate asthma severity has been defined as: $FEV_1 \geq 60\%$, Peak Expiratory Flow Rate (PEFR) > 20%, and an increase in FEV_1 of 15% following inhaled 200μg salbutamol by metered dose inhaler (MDI). Those subjects who had an emergency room visit within the last 3 months, a hospital stay within the last year, and if they have been on oral steroids within the last month did not fit the criteria for mild to moderate asthma (Juniper, Johnston et al. 1995). Similarly in their definition of mild to moderate asthmatics, Hyland, Kenyon and Jacobs (1994) included FEV_1 values of 15% following inhaled 200μg Salbutamol by MDI, and excluded those subjects on oral or inhaled corticosteriods and PEFR > 75% predicted value. Moderate asthmatics were defined as having an FEV_1 between 50-80 % of the predicted value, using an inhaled medication for at least 6 months, and an oral or inhaled $beta_2$-bronchodilator for at least 2 weeks prior to the study and no oral steroid use (Mahajan et al.1997).

Apter and colleagues (1996) defined moderate to severe asthmatics using the National Heart, Lung and Blood Institute Guidelines in which at least four of seven criteria listed must be met. This criteria includes: medication usage, reduced exercise tolerance, school or work attendance which is compromised and regular use of antiinflammatory medications required for prolonged periods. Recent hospitalization and emergency room visits has been used to delineate moderate from severe asthma (Boulet et al. 1995; Gibson, Talbot & Toneguzzi, 1995). Severe asthma has been defined as FEV_1 values between 40 - 80% of the predicted value and the use of the oral steroid prednisone (Okamoto et al. 1996).

The selection of an instrument to measure QOL appears to be based on the researchers preference and on available tools at the start of the research project. In longitudinal medication clinical trials, a positive relationship between disease severity and quality of life was found in eight of nine studies (Apter et al. 1996; Hyland, Kenyon, & Jacobs, 1994; Jones et al. 1994; Juniper, Johnston et al. 1995; Mahajan et al. 1996; Marin, Carrizo, Garcia & Ejea, 1996; Okamoto et al. 1996; Rutten-van Molken et al. 1995). Few studies have done cross-sectional, descriptive research on adult asthmatics. Disease severity has been defined somewhat differently in each research study. Although asthma severity has been associated with QOL, gender has not been clearly recognized as an important variable to study. The various domains inherent in QOL tools has not been clearly described or explored in relationship to gender or disease severity.

CHAPTER THREE

Method

This chapter includes information on the sample, the tools for data collection, reliability and validity of the tools, data collection procedures, data analysis, and ethical considerations.

Research Design

Secondary analysis is research involving the re-analysis of data to either answer the original research question with improved statistical techniques or to answer new research questions with the same data (Glass, 1976; Polit & Hungler, 1993). Secondary analysis has several advantages. It enables access to larger data bases and closer examination of subunits of data, it is economical, speeds data collection and simplifies the logistics of research (Heron, 1989). Secondary analysis was used in this study to explore new research questions.

A nonexperimental, exploratory design was used to address the research questions. Secondary analysis was conducted on a subset of data drawn from a larger project entitled the "Asthma-Anxiety Project" (Ross & Davis, 1997). Volunteers for the Asthma-Anxiety Project participated in a single, four hour interview during which time a series of questionnaires were administered to collect data including: demographics, asthma history and quality of life.

Sample

The sample for the "Asthma-Anxiety Project" was comprised of 91 adult asthmatic patients who visited a pulmonary specialist in an asthma clinic in the Capital Health

Authority Region between May and August 1997. Patients were eligible for the study if they were 18 years of age or older, able to speak and understand English, and had met one or more of the diagnostic criteria for asthma based on the Canadian Asthma Consensus Guidelines (Ernst, Fitzgerald & Spier, 1996). For the purpose of this study, raw data was drawn from 56 of the 91 subjects who were screened to rule out anxiety disorders. This subset of data, will be referred to as the total sample for the remainder of these chapters.

Procedure

Data collection for the Asthma-Anxiety Project occurred following ethical approval from the appropriate institutional boards. During a scheduled visit to see the pulmonary specialist, adult patients who met inclusion criteria were approached by a health professional employed at the clinic to determine if they would be willing to be accessed by a nurse-researcher associated with the Asthma-Anxiety Project. Patients who provided access permission were introduced to a nurse-researcher who explained the study and invited their informed consent. All volunteers were contacted by telephone to negotiate a suitable time for an interview with a research assistant.

At the time of the interview, written consent was obtained (Appendix A). During the interview, several interview guides were used to collect demographic and clinical information. Subjects were screened for anxiety disorders using the Anxiety Disorders Interview Schedule-IV (Barlow & DiNardo, 1994). In addition, subjects completed two quality of life questionnaires.

Instruments

Sample Characteristics

Demographic data were collected using a form developed by the primary researchers for the purpose of data collection in the larger study (Appendix B). Demographic variables included in the secondary analysis were the subject's age, gender, education, annual combined household income, marital status and the number of individuals who shared their living space. These demographic variables have been found to be associated with quality of life (Ferrans & Powers, 1985; Juniper, Guyatt, Epstein, Ferrie, Jaeschke & Hiller, 1992).

A number of clinical characteristics were drawn from data collected using the Asthma Questionnaire developed for the Prairie Provinces Asthma Study: 1992-1995, conducted by Tough, Hessel, Green, Mitchell, But and Ruff (1996). Only specific clinical characteristics related to asthma, including disease history, symptoms, severity, medications, and health care utilization were drawn from the questionnaire for secondary analysis (Appendix C).

The Quality of Life Index - Respiratory Version

Quality of life is defined by Ferrans and Powers (1992) as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 29). The Quality of Life Index - Respiratory Version (QLI-RV) developed by Ferrans and Powers (1992) was utilized to assess the quality of life of adult asthmatic patients in this study (Appendix D). The QLI-RV was developed from a generic Quality of Life Index (QLI) that was used to measure the quality of life of healthy

individuals. The Quality of Life Index questionnaire is a discriminative (designed to differentiate between people), cross-sectional, subjective scale, that provides quantitative data on quality of life (Guyatt, Feeny & Patrick, 1993; Padilla & Frank-Stromborg, 1997).

The QLI was first tested using a group of healthy graduate students (n = 88) (Ferrans & Powers, 1985). Using factor analysis procedures, Ferrans and Powers (1992) found the following four domains within the QLI: health and functioning, socioeconomic, psychological/spiritual, and family. Content validity for the QLI was established through a review of the quality of life literature. Convergent validity was demonstrated by a coefficient of .77 when the QLI total score was correlated with a single item rating of satisfaction with life (Ferrans & Powers, 1985; 1992). A two-week test-retest reliability was .87 using a sample of graduate nursing students. The reported Cronbach alpha's were greater than .90 for the overall score and .70 for the individual domains (Ferrans & Powers, 1985; 1992). Ferrans and Powers have concluded that the QLI is a valid and reliable tool for use with healthy adults and when modified, for chronic illness groups .

Ferrans and Powers (1992) have developed a tool that has the ability to measure quality of life in four domains, as well as overall quality of life. The QLI has been modified for use with other illness groups. Reliability and validity data has been published for a hemodialysis version (Ferrans & Powers, 1985; 1993; Bihl, Ferrans & Powers, 1988); a cancer version (Arzouman, Dudas, Ferrans & Holm, 1991; Belec, 1992); a cardiac version (Bliley & Ferrans, 1993; Daumer & Miller, 1992; Wingate, 1995) and a transplant version (Hicks, Larson & Ferrans, 1992). The tool is also available for use with respiratory, diabetes, arthritis, stroke/head injury, burn, epilepsy, narcolepsy, multiple

sclerosis, spinal cord injury/ quadriplegic, urostomy, and kidney transplant patients. All of these versions are similar to the generic version with questions added to the core items to address the issues specific to each group.

The respiratory version of the QLI has two additional items related to the ability to breathe without shortness of breath and are found in the health and functioning domain. The QLI-RV is a 70-item self-reported instrument that includes the domains: health and functioning (15 items: questions 1 - 8, 13, 16, 17, 18, 26, 27, 28), socioeconomic (9 items: questions 14, 15, 19, 20, 21, 22, 23, 24, 25), psychological/ spiritual (7 items: questions 29 -35), and family (4 items: questions 9 - 12). Consistent with the QLI, the QLI-RV is divided into two sections, one section measures an individual's satisfaction with the various domains in their life, and the other measures how important those domains are to that individual. Subjects respond to each item on a six-point likert scale ranging from 1 (very dissatisfied) to 6 (very satisfied), in the satisfaction section and from 1 (very unimportant) to 6 (very important) for the importance items. Scoring of the instrument requires that the satisfaction scores be recoded to center the scale on zero by subtracting 3.5 from the satisfaction response for each item. Satisfaction scores are then adjusted by multiplying paired satisfaction scores with the importance scores. The overall score is obtained by summing all adjusted scores and dividing the number by the items answered (this accounts for any missing items). To eliminate negative scores, 15 is added to every score. This weighted score reflects individual's values, as well as, satisfaction which produces a more accurate reflection of quality of life (Ferrans & Powers, 1992). The highest scores occur with the combination of high satisfaction/ high importance

responses which reflects the belief that the greatest satisfaction with highly important areas of life contributes to a higher quality of life. Great dissatisfaction with highly important areas of life suggests a lower quality of life. Scores can range from zero to 30, with higher scores reflecting a higher perceived quality of life.

Although this tool can be considered a disease-specific quality of life tool for respiratory illness, this tool is not specific to asthmatic patients. The use of the QLI-RV and its particular psychometric properties has not been published in the literature (Ferrans & Powers, 1992).

The interpretation of scores for the QLI-RV and the domains is a vital component in assessing an individual's quality of life. Although statistically significant differences may be found when analyzing the score of the QLI-RV and domains, the clinical significance of these scores is necessary to determine how these results affect the individual and subsequently clinical practice. The recognition of clinically significant differences will facilitate the evaluation of whether an individual has a higher or lower quality of life compared to others with similar circumstances or disease. A difference of two points in the mean scores and domain scores on the QLI-RV can be considered a clinically significant difference (C. E. Ferrans, personal communication, March 6, 1998).

Asthma Quality of Life Questionnaire

The Asthma Quality of Life Questionnaire (AQLQ) was the second tool utilized to describe the quality of life of adult asthmatics (Appendix E). Juniper (1995) defines disease-specific quality of life as "the way patients feel and how they function in their day-to-day lives as the result of their disease" (p. 3). The AQLQ was designed as an

evaluative instrument to measure small, within subject, changes over time. This tool can also be utilized as a discriminative instrument, to measure differences between subjects (Juniper, Guyatt, Ferrie & Griffith, 1993; Juniper, Johnston et al. 1995; Malo et al. 1993).

The AQLQ was developed through a review of the literature and interviews with both respiratory physicians and asthmatic patients (Juniper, Guyatt, Epstein, et al. 1992). The final questionnaire has four domains that include: symptoms, emotional function, activity limitation and exposure to environmental stimuli. Content validity was established through the process in which the questionnaire was developed and the representation of domains that are important to asthmatics themselves.

There have been a limited number of published articles regarding the psychometric properties of the AQLQ. Research studies, utilizing the AQLQ, have been conducted to assess the effect of medications on quality of life (Apter et al. 1996; Juniper, Johnston et al. 1995); to assess self-management and autonomy on quality of life (Gibson, Talbot & Toneguzzi, 1995) and to assess the validity and reliability of the AQLQ in an out patient setting (Rowe & Oxman, 1993).

Juniper and colleagues (1993) have found that the AQLQ is sensitive enough to detect not only changes in quality of life within adult asthmatics over a period of time, but also differences in quality of life between subjects. Test retest reliability was conducted, with a four week interval, on a group of stable asthmatics with a correlation of .92 supporting the AQLQ as a "one time only" measure of quality of life. Convergent validity has been reported as .73 between the AQLQ and the Living With Asthma Questionnaire (LWAQ), an other disease specific quality of life instrument (Rutten-van Molken et al.

1995). Juniper and colleagues (1993) concluded that the AQLQ is a valid instrument for both evaluative and discriminative purposes.

To begin the AQLQ, subjects are asked to identify five significant activities that are limited because of their asthma. A list of 27 activities is provided to the subjects to facilitate a response but this is not considered exhaustive. These activities include dancing, talking, and walking upstairs or uphill. Once five activities are identified, subjects are then asked about the extent to which they have been limited in performing each activity by rating them on a likert scale from 1 (totally limited) to 7 (not at all limited). Twenty-seven other questions address issues related to their asthma. The AQLQ is comprised of a total of 32 items in four domains: activity limitation (11 items: questions 1, 2, 3, 4, 5, 11, 19, 25, 28, 31, 32), symptoms (12 items: questions 6, 8, 10, 12, 14, 16, 18, 20, 22, 24, 29, 30), emotional (5 items: questions 7, 13, 15, 21, 27) and environmental stimuli (4 items: questions 9, 17, 23, 26). Individual items within the AQLQ are equally weighted. Results are expressed as a mean score from 1 (maximum impairment to quality of life) to 7 (minimum impairment to quality of life) for each domain, as well as for a total score which facilitates the interpretation of results. For example, the results from a domain with 4 items and a domain with 11 items will both be expressed as a score from 1 to 7. The overall quality of life score is calculated from the mean score of all the items.

Juniper, Guyatt, Willan and Griffith (1994) have identified a minimally important change of .5 in the AQLQ or domain scores as representative of an important improvement or deterioration in quality of life. Differences of approximately 1.0

represent a moderate change and differences greater than 1.5 represent a large change. The minimally important difference (MID) has been used to define clinical significance for within subject changes of quality of life (Juniper et al. 1994) and between subject changes (Malo et al. 1993). Further research, comparing other groups of asthmatic subjects would provide more information for interpreting the magnitude of such differences between subjects.

Disease Severity

Objective Asthma Severity. The Asthma Severity Risk Index (ASRI) was used to categorize patient's asthma severity (Appendix F). The ASRI is a weighted scoring procedure developed by Janson-Bjerklie and colleagues (1992). The weighted score for each subject is based on several variables shown to be associated with asthma-related fatalities including: the number, type and route of medications taken to control asthma symptoms; previous hospitalizations within the past year and the need for intubation. Those items given greater weight, e.g. intubation, are associated with higher risk for asthma-related death (Sears, 1988, Strunk, 1989). Potential scores can range from zero to 25, with a score of 25 indicating very severe asthma.

In research conducted by Janson-Bjerklie, Ferketich, Benner and Becker (1992) on 95 adult asthmatics, a statistically significant relationship was found between the total weighted score on the ASRI and other objective measures of asthma severity, e.g. symptom episodes ($r = .33$), report of sleep disturbances ($r = .26$) and spirometric measures, FEV_1 ($r = -.28$). When the ASRI was simply summed (unweighted score), the correlation was even stronger with FEV_1 ($r = -.57$). This demonstrated further support for

the association between asthma risk and asthma severity. This tool is a quick and simple way to objectively identify asthma severity, and it has been demonstrated to be a valid and reliable tool.

Subjective Asthma Severity. Subjective asthma severity refers to the individual's own evaluation of their disease (Nguyen, Wilson & German, 1996). Raw data on subjective asthma severity was drawn from responses to one item in the Asthma Questionnaire: "How would you rate the overall severity of your asthma condition?" Three fixed-alternative options were offered as follows: severe (seriously interferes with normal lifestyle), moderate (occasionally interferes with normal lifestyle), and mild (infrequently interferes with normal lifestyle).

Data Analysis

Data was prepared for analysis by coding all questions and entering responses into the computer. A code book was utilized to guide this process. All data were coded by the investigator and entered into a data file using the Statistical Package for Social Sciences (SPSS) for Windows 7.0 (Norusis, 1996). All data was rechecked to ensure accuracy of data entry. Frequency tables were run for every variable, in order to check for inconsistencies. The final data file is considered to be free of coding errors. The conventionally accepted level for Type I error ($p \leq .05$) was used throughout the data analysis.

Sample Characteristics

Descriptive statistics were used to summarize demographic and clinical variables. Interval data including age, and the number of years since asthma diagnosis were

summarized using mean, standard deviation and range. Nominal data, including fixed-alternative responses were summarized using frequencies and percentages. Gender differences on demographic and clinical variables were examined using independent t-test analysis for the continuous variables and chi-square analysis for nominal data.

Asthma and Quality of Life

The quality of life of adults with asthma was determined using the QLI-RV and the AQLQ. Both tools were scored according to established procedures previously outlined. All quality of life scores were considered continuous data and were summarized using mean, standard deviation and range.

Gender and Quality of Life

Parametric statistics were used to test the null hypothesis. Gender differences and quality of life were examined by comparing the mean of the overall score and each domain for the QLI-RV and the AQLQ using independent t-tests with Levine's correction for inequality of variance. Clinically significant differences were identified by a two point difference between the mean scores for women and men on the overall score and domain scores for the QLI-RV, and a .5 difference on the total score and domain scores for the AQLQ.

Disease Severity and Quality of Life

Objective Asthma Severity. Frequencies and percentages were calculated for the ASRI. To facilitate data analysis, subjects with scores at or below the median of two were placed into the low objective asthma severity (OAS) group. Those with a score greater than the median were placed into the high OAS group.

Subjective Asthma Severity. Frequencies and percentages were also calculated for subjective asthma severity. Similar to OAS, subjects were placed into either a low or high subjective asthma severity (SAS) group based on how they perceived their asthma severity. Those who rated their severity as mild were placed in the low SAS group and those who rated their severity as moderate or severe were placed in the high SAS group.

High and low OAS groups were compared on the mean total score and domain scores of both the QLI-RV and the AQLQ using independent t-tests with Levine's correction for inequality of variance. High and low SAS groups were then similarly compared on quality of life measures.

Gender and Asthma Severity

Gender and asthma severity was examined using an independent t-test for the ASRI and chi-square for the three subjective disease severity groups. Comparison of gender groups based on OAS and SAS were then examined using chi-square analysis.

Ethical Considerations

Secondary analysis was done following ethical approval from the Health Research Ethics Administration Board (HREAB), a joint committee of the University of Alberta Health Sciences Faculties, the Capital Health Authority, and the Caritas Health Group. The original consent form, signed by all the subjects in the larger study, identified that data collected may be considered for secondary analysis with the appropriate ethical consent (Appendix A).

No contact was made with subjects from the original study. Confidentiality was maintained as only code numbers were utilized to identify data. There were no risks or

immediate benefits for the subjects in this study. Information may be published or presented at conferences. No information that identifies individual subjects will be reported. Individual questionnaires will be held by the primary researchers of the Asthma-Anxiety project, in accordance with University of Alberta policy.

CHAPTER FOUR

Findings

The results of the data analysis are presented in this chapter. First, the demographic and clinical characteristics of the sample are described. Second, each of the research questions are presented with their respective results. Other findings complete this chapter.

Demographic Characteristics

Demographic characteristics are summarized in Table 1 for the total sample and for each gender group. Demographic characteristics included age, marital status, living arrangements, highest education level, annual combined income, and the presence of another illness. The total sample (N = 56) had a mean age of 47.46 years (SD = 14.87, range = 18 - 76). The majority of subjects (n = 47, 94 %) live with at least one other person (spouse, children, parents or siblings). The largest frequency response for level of education was a high school diploma (n = 26, 46 %). Sixty-one percent of the sample had a combined annual income of $50,000 or less (n = 34). Of the 25 (45%) subjects that identified having another illness, 12 had diseases related to the cardiac system (e.g. hypertension, congestive heart failure, mitral stenosis), four were diabetic, three had irritable bowel syndrome, and two had been previously diagnosed with breast cancer. The remaining four subjects had illnesses that included hypothyroidism (two), seizures and sleep disorder.

There were 34 females and 22 males in this study. The women in this sample had a mean age of 49.26 years (SD = 14.65, range 19 -76) and the men had a mean age of 44.68

years (SD = 15.11, range 18 - 70). Ten women in the sample were either single or widowed. Only two of the men identified themselves as single, and none were widowed. All of the individuals who identified themselves as living alone were female. The largest frequency response for living arrangements reported by women was 'living with their spouse' (n = 13, 38 %), while the majority of the men live with their spouse and children (n = 13, 59 %). More women in the group have completed post secondary education (n = 16, 47 %) compared to men (n = 7, 33 %). An annual combined income of $31,000 to $50,000 was the largest frequency response for women (n = 12, 36 %) and men (n = 7, 31 %). Half of the women (n = 17, 50 %) and over one third of the men (n = 8, 36 %) reported having another illness. Of the 17 women who identified other illness, seven had cardiac disease, three were diabetic, three had irritable bowel disease, two had a history of breast cancer, and two had hypothyroidism. The eight men who reported other illnesses, included five with cardiac disease, one was a diabetic, one had a seizure disorder, and one had a sleep disorder.

Clinical Characteristics

Clinical characteristics of the sample and for each gender group are displayed in Table 2. Clinical characteristics of the sample were described in terms of age diagnosed with asthma, number of years diagnosed, morning symptoms, night symptoms, mucus production, emergency room visits, hospitalizations and if the subjects had ever received cardiopulmonary resuscitation (CPR). The mean age of the sample when initially diagnosed with asthma was 32.73 (SD = 22.74, range = infancy to 70). Ten subjects (18%) had been diagnosed with asthma within the past year (M = 56, SD = 10.4, range =

36 - 64). In the past two weeks, the majority of the sample (n = 31, 55 %) had coughing, wheezing or chest tightness when waking up in the morning (a.m. symptoms), and they did not wake-up during the night to use their asthma medication (p.m. symptoms) (n = 48, 86%). The majority of the sample (n = 30, 54 %) also identified often having mucus or phlegm in their chest that needed to be coughed up (mucus production). The majority of the sample have gone to the emergency room (ER) at some point due to asthma symptoms (n = 35, 63 %), while only 22 (39 %) have ever been hospitalized for their asthma. Only one individual, a female, has had CPR and was intubated due to a severe asthma attack.

The mean age of asthma diagnosis for females was 36.88 (SD = 21.93, range = infancy - 64), and the mean age for men was approximately 10 years later (M = 26.32, SD = 22.96, range = infancy - 70). The eight females newly diagnosed in the past year had a mean age of 53.38 years (SD = 10.10, range 36 -64) while the two men newly diagnosed in the past year were aged 63 and 70 years (M = 66.50, SD = 4.95). Twenty-six women (77 %), diagnosed with asthma for greater than one year had a mean age of 31.81 years (SD = 22.19, range = infancy - 66). Twenty men (90 %), diagnosed with asthma for greater than one year had a mean age of 22.30 years (SD = 19.87, range = infancy - 58). More women (n = 17, 50 %) than men (n = 8, 36 %) were free of a.m. symptoms. Greater than 70 % of both genders were free of p.m. symptoms. A greater percentage of the men (n = 15, 68 %) compared to women (n = 19, 56 %) reported a frequent need to clear mucus from their chest. More women (n = 22, 65 %) than men (n = 9, 41 %) have been hospitalized for their asthma. No one in the group had been hospitalized in the past three months.

All 56 subjects in this sample were currently taking medications to control their asthma and were under the care of the same respiratory physician. All subjects were currently using a inhaled $beta_2$-agonist medication (e.g. salbutamol or salmeterol) to control symptoms. An inhaled steroid medication was taken everyday by 53 (95%) of the subjects. Three of the subjects were currently taking oral prednisone for their asthma (all female) and 5 subjects have been on oral prednisone in the past three months (3 males and 2 females). Thirty-four (61%) have taken oral steroids at some point during the course of their disease (22 women and 12 men).

No statistically significant differences were found between gender on age ($t = 1.130$, $p = .26$), age diagnosed with asthma ($t = 1.729$, $p = .09$) or number of years since diagnosed with asthma ($t = -1.377$, $p = .14$). Chi-square analysis was conducted on gender and the demographics: marital status ($\chi^2 = 3.74$, $df = 2$, $p = .15$); living arrangement ($\chi^2 = 7.45$, $df = 3$, $p = .06$), education ($\chi^2 = 1.79$, $df = 2$, $p = .41$); annual household income ($\chi^2 = 4.81$, $df = 4$, $p = .31$), and other illness ($\chi^2 = .742$, $df = 1$, $p = .42$). There were no statistical differences found.

Chi-square analysis was conducted on gender and the clinical characteristics: a.m. symptoms ($\chi^2 = 2.756$, $df = 4$, $p = .60$); p.m. symptoms ($\chi^2 = 5.690$, $df = 2$, $p = .06$); mucus production ($\chi^2 = 3.11$, $df = 1$, $p = .08$); ER visits ($\chi^2 = .18$, $df = 1$, $p = .67$); hospitalizations ($\chi^2 = .077$, $df = 1$, $p = .78$), and ever having CPR ($\chi^2 = .680$, $df = 1$, $p = .41$). There were no statistical differences found.

Quality of Life

Question 1: What is the quality of life of adults with asthma who have been referred to a pulmonary specialist in a Canadian out-patient setting?

Quality of Life Index - Respiratory Version (QLI-RV). The mean score, standard deviation, and range for the overall QLI-RV and domains are reported in Table 3. Two of the subjects did not complete the last page of the questionnaire and were therefore excluded from the analysis of this tool (n = 54). The domain with the highest mean score was family (M = 25.50, SD = 4.98). The domain with the lowest mean score was health and functioning (M = 22.89, SD = 4.32). The socioeconomic domain and the psychological/ spiritual domain had the widest range of scores from 7.2 to 30.0 and 7.6 to 30.0 respectively.

Asthma Quality of Life Questionnaire (AQLQ). The mean score, standard deviation, and range for the overall AQLQ and the individual domains are reported in Table 4. One subject missed a question and therefore was excluded from the analysis of the overall score and the environmental domain in which the item was missed (n = 55). The five most frequently identified individualized activities that were impaired because of asthma were: walking upstairs/ uphill (n = 19); mowing the lawn/gardening (n = 15); jogging/ exercising/ running (n = 14); going for a walk (n = 14) and doing housework (n = 14).

The highest mean score of the AQLQ was on the emotional domain (M = 5.92, SD = 1.11). The lowest mean score was on the activity domain (M = 5.49, SD = 1.19). The

symptom domain and the environmental domain had the widest range of scores at 2.08 to 7.00 and 2.50 to 7.00 respectively.

Gender Differences and Quality of Life

Question 2: Are there differences between women and men with asthma and quality of life?

Gender and QLI-RV. The overall QLI-RV and domain mean scores, standard deviations and ranges for gender are displayed in Table 5. The lowest mean score for both women (M = 22.9, SD = 4.62) and men (M = 22.74, SD =3.95) was on the health and functioning domain. The highest mean score for both women (M = 25.43, SD = 5.68) and men (M = 25.59, SD = 3.86) was on the family domain.

Mean scores were slightly higher for women than men for the overall score and all the domains except family. The range of scores for both the overall QLI-RV and domains was wider for women than for men. No statistically significant differences were found between gender and the overall QLI-RV mean score or domain scores (Table 5). The clinical differences between gender on the overall QLI-RV and domain mean scores were: overall score .24; socioeconomic domain .43; psychological/ spiritual domain .65; health and functioning domain .25 and family domain .16. All mean differences were less than two, indicating no clinically significant differences were found between gender and quality of life using the QLI-RV.

Gender and AQLQ. The overall AQLQ and domain mean scores, standard deviations and ranges for gender are displayed in Table 6. For women, the five activities most often identified as limited by their asthma were: doing housework (n = 13); walking

up stairs or up hills (n = 12); going for a walk (n = 12); jogging or exercising (n = 12) and gardening (n = 7). For men, the five activities were: mowing the lawn (n = 7); jogging or exercising (n = 7); bicycling (n = 6) and doing home maintenance or playing sports (n = 4). The lowest mean score for both women (M = 5.56, SD = 1.17) and for men (M = 5.38, SD = 1.23) was on the activity domain. The highest mean score for both women (M = 5.96, SD = 1.03) and men (M = 5.85, SD = 1.25) was on the emotional domain.

All mean scores were slightly higher for women than for men. Ranges in scores were similar for men and women. No statistically significant differences were found between gender on the overall AQLQ or domain mean scores (Table 6). The clinical differences between gender on the overall AQLQ and the domain mean scores were: overall score .22, environmental domain .13, emotional domain .11, symptom domain .36, and activity domain .18. All mean differences were less than .5 indicating no clinically significant differences were found between gender on quality of life using the AQLQ.

Disease Severity

Objective Asthma Severity. The Asthma Severity Risk Index (ASRI) scores for the sample and by gender are reported in Table 7. Scores ranged from 1 to 17 with a mean of 2.84 (SD = 2.30). The two highest scores were individually, an 8 and a 17. Women had the three highest scores on the ASRI and reported a wider range of scores with a mean of 3.03 (SD = 2.82). The female subject who scored 17 was the only subject who was previously intubated for asthma. The range for men on the ASRI was 1 to 5 with a mean of 2.55 (SD = 1.10). No statistically significant differences were found between gender on the ASRI ($t = .24$, $p = .45$).

When ASRI scores were divided into low and high groups the majority of the sample (n = 36, 64%) were placed in the low OAS group (Table 9). When ASRI scores for gender were divided into low and high groups the majority of women (n = 21, 62 %) and men (n = 15, 68 %) had low OAS (Table 9). There were no statistically significant differences between gender on OAS (χ^2 = .240, df = 1, p = .76).

Subjective Asthma Severity Results for the total sample, and by gender, on subjective asthma severity, are reported in Table 8. The largest number of subjects perceived their asthma as low (n = 27, 48 %). No statistically significant differences were found between gender on the item assessing perceived asthma severity (χ^2 = .346, df = 2, p = .84).

When the three categories of subjective asthma severity were divided into two groups the majority of subjects (n = 29, 52 %) were placed in the high SAS group (Table 9). Half of the women (n = 17, 50 %) and more than one third of the men (n = 10, 46 %) were placed in the low SAS group. There were no statistically significant differences between gender and SAS (χ^2 =.111, df = 1, p = .79). Given the lack of gender differences on quality of life and measures of asthma severity further analysis of relationships between asthma severity and quality of life were collapsed across gender.

Disease Severity and Quality of Life

Question 3: Do asthmatics with low objective asthma severity compared to those with high objective asthma severity differ in quality of life?

Objective Asthma Severity and QLI-RV. The overall QLI-RV and domain mean scores, standard deviations and ranges for low and high OAS are reported in Table 10.

The lowest mean score for low OAS (M = 23.35, SD = 4.59) and high OAS (M = 22.02, SD = 3.73) were found on the health and functioning domain. The highest mean scores were found on the family domain for low OAS (M = 24.99, SD = 5.47) and high OAS (M = 26.42, SD = 3.89).

The scores on the overall QLI-RV and for the socioeconomic, psychological/ spiritual and the family domain were slightly higher for those identified with high OAS than those with low OAS. There were no statistically significant differences between subjects grouped by OAS on the QLI-RV or any of the domains (Table 10).

The clinical difference between low and high OAS groups and the overall QLI-RV and domain mean scores were: overall score .24; for the socioeconomic domain .67; for the psychological/ spiritual domain .35; for the health and functioning domain 1.33 and for the family domain 1.43. There were no clinically significant differences between subjects grouped by OAS on quality of life. The correlation between the scores on the ASRI and the overall QLI-RV were not statistically significant ($r = -.16$, $p = .23$).

Objective Asthma Severity and AQLQ. The overall AQLQ and domain mean scores, standard deviations and ranges for subjects by OAS are reported in Table 11. The lowest mean score for low OAS (M = 5.65, SD = .94) and high OAS (M = 5.21, SD = 1.52) were on the activity domain. The highest scores were on the emotional domain for both low OAS (M = 6.18, SD = .94) and high OAS (M = 5.45, SD = 1.26).

The mean scores on the overall AQLQ and each of the four domains are higher for the low OAS compared to high OAS. There were no statistically significant differences between subjects grouped by OAS on the overall AQLQ score or the environmental,

symptom or activity domains (Table 11). Those categorized as low OAS (M = 6.18, SD = .94) had a statistically significant (p = .02) higher score on the emotional domain compared to subjects with high OAS (M = 5.45, SD = 1.26).

There were no clinically significant differences between low and high OAS and the domains environment (.44), emotional (.43) and activity (.44). There was a clinically significant difference between low and high OAS on the overall score of the AQLQ (.5) and on the emotional domain (.73). The correlation between the scores on the ASRI and the overall AQLQ were statistically significant (r = -.34, p = .01).

Question 4: Do asthmatics with low subjective asthma severity compared to those with high subjective asthma severity differ in quality of life?

Subjective Asthma Severity and QLI-RV. The overall QLI-RV and domain mean scores, standard deviations and ranges for subjects grouped in two for SAS are reported in Table 12. The lowest mean score for low SAS (M = 24.91, SD = 3.77) and high SAS (M = 21.00, SD = 3.99) were found on the health and functioning domain. The highest mean scores were found on the family domain for both low SAS (M = 25.62, SD = 4.03) and high SAS (M = 25.39, SD = 5.8).

The mean scores on the overall QLI-RV and the four domains are all higher for low SAS compared to high SAS. There were no statistically significant differences between subjects grouped by SAS in the QLI-RV socioeconomic, psychological/ spiritual or family domains. Those categorized as low SAS had a significantly higher score on the total score of the QLI-RV (p = .01) and the health and functioning domain (p = .0001) compared to those subjects with a high SAS.

The clinical difference between subjects, grouped by high and low SAS, on the overall QLI-RV and each domain were: overall, 2.59; socioeconomic domain, 1.98; psychological/ spiritual domain, 1.56; health and functioning domain, 3.9; and the family domain, .23. There were clinically significant differences for the overall QLI-RV and for the health and functioning domain.

Subjective Asthma Severity and AQLQ. The overall AQLQ and domain mean scores, standard deviations and ranges for low and high SAS are reported in Table 13. The lowest mean score for low SAS (M = 5.87, SD = .85) was on the environment domain. The lowest mean score for subjects grouped as high SAS was on the activity domain (M = 5.00, SD = 1.26). The highest mean scores were found on the emotional domain for both low SAS (M = 6.31, SD = .67) and high SAS (M = 5.56, SD = 1.3).

The mean scores on the AQLQ and the four domains are all higher for subjects with low SAS compared to high SAS. Statistically significant differences were found between subjects grouped by SAS on the overall AQLQ and all four domains (Table 13). The clinical differences between subjects grouped by high and low SAS for the overall AQLQ and domain mean scores were: overall score .88, for the environmental domain .61; for the emotional domain .75, for the symptom domain .90 and for the activity domain 1.02. There were clinically significant differences for the overall AQLQ and all four domains. Statistically significant correlation's were found between the subjective asthma severity categories and the overall QLI-RV ($r = .36$, $p = .007$, $p < .01$) and for the overall AQLQ ($r = .56$, $p = .0005$, $p < .01$).

Other Findings

Psychometric Properties of the QLI-RV and the AQLQ

Chronbach's alpha coefficients were calculated for the overall QLI-RV and each domain and are displayed in Table 3. Chronbach's alpha coefficients were calculated for the overall AQLQ and each domain and are displayed in Table 4.

The Relationship between the QLI-RV and the AQLQ

The correlation between scores on the overall QLI-RV and on the overall AQLQ were statistically significant ($r = .36$, $p = .007$).

The Relationship between the ASRI and Subjective Disease Severity

When divided into low and high OAS and SAS, 35 (63 %) of the subjects were grouped in the same category for objective and subjective asthma severity. Six (11 %) of the total sample, that were placed in the low SAS group, were placed in the high OAS group. This included 4 (12 %) women and 2 (32 %) men. Fifteen (27 %) of the total sample that were placed in the high SAS group were placed in the low OAS group. This included 8 (24 %) women and 7 (32 %) men. The correlation between the ASRI and the subjective asthma severity category were not statistically significant ($r = -.22$, $p = .107$).

Table 1

Demographic Characteristics of Sample

Demographic Characteristics	Total Sample (n = 56)	Female (n = 34)	Male (n = 22)
marital status			
married/ common law	44 (79 %)	24 (71 %)	20 (91 %)
single	9 (16 %)	7 (21 %)	2 (9 %)
widowed	3 (5 %)	3 (9 %)	-
living arrangement			
alone	7 (13 %)	7 (21 %)	-
spouse	19 (34 %)	13 (38 %)	6 (27 %)
spouse & children	24 (43 %)	11 (32 %)	13 (59 %)
parents and siblings	4 (17 %)	2 (6 %)	2 (9 %)
highest education level			
grades 7 - 11	7 (13 %)	3 (9 %)	4 (18 %)
high school diploma	26 (46 %)	15 (44 %)	11 (50 %)
post secondary degree	23 (41 %)	16 (47 %)	7 (33 %)
annual combined income			
< $30,000	15 (27 %)	11 (32 %)	4 (18 %)
$31,000 - $50,000	19 (34 %)	12 (36 %)	7 (31 %)
$51,000 - $70,000	9 (16 %)	5 (15 %)	4 (18 %)
$71,000 - $90,000	5 (14 %)	1 (3 %)	4 (18 %)
> $91,000	6 (11 %)	3 (9 %)	3 (13%)
other illnesses			
no	30 (54 %)	17 (50%)	13 (59%)
yes	25 (45 %)	17 (50%)	8 (36%)

Numbers may not add to total due to missing or not applicable coding.
Percentages have been rounded to the nearest whole number.

Table 2

Clinical Characteristics of Sample

Clinical Characteristics	Total Sample (n = 56)	Female (n = 34)	Male (n = 22)
number of yrs diagnosed			
1 year or less	10 (18 %)	8 (24 %)	2 (9 %)
greater than 1 year	46 (82 %)	26 (77 %)	20 (90 %)
a.m. symptoms			
never	25 (45 %)	17 (50 %)	8 (36 %)
1 to 3 mornings	12 (21 %)	6 (18 %)	6 (27 %)
4 to 8 mornings	11 (20 %)	7 (21 %)	4 (18 %)
9 to 13 mornings	1 (2 %)	-	1 (5 %)
every morning	7 (13 %)	4 (12 %)	3 (14 %)
p.m. symptoms			
never	48 (86 %)	32 (94 %)	16 (73 %)
1 to 3 nights	6 (11 %)	1 (3 %)	5 (23 %)
4 to 8 nights	2 (4 %)	1 (3 %)	1 (5 %)
mucus production			
no	26 (46 %)	19 (56 %)	7 (32 %)
yes	30 (54 %)	15 (44 %)	15 (68 %)
ever gone to ER			
no	21 (38 %)	12 (35 %)	9 (40 %)
yes	35 (63 %)	22 (65 %)	13 (59 %)
ever been hospitalized			
no	27 (48 %)	17 (50 %)	10 (46 %)
yes	22 (39 %)	22 (65 %)	9 (41 %)
ever had CPR			
no	49 (88%)	29 (85 %)	20 (91 %)
yes	1 (2%)	1 (3%)	-

Numbers may not add to total due to missing or not applicable coding.
Percentages have been rounded to the nearest whole number

Table 3

Quality of Life Index - Respiratory Version

QLI - RV Scale (N = 54)	M	SD	Range	Reliability Coefficient
Overall score	23.59	3.73	10.4 - 28.9	.90
Socioeconomic	24.12	4.51	7.2 - 30.0	.82
Psychological/ Spiritual	24.24	4.07	7.6 - 30.0	.87
Health & Functioning	22.89	4.32	13.6 - 29.4	.90
Family	25.50	4.98	8.0 - 30.0	.62

Scores range from 0 to 30 with a score of 30 indicating higher perceived quality of life.

Table 4

Asthma Quality of Life Questionnaire

AQLQ Scale	N	M	SD	Range	Reliability Coefficient
Overall score	55	5.63	.99	3.00 - 6.94	.92
Environmental	55	5.56	1.13	2.50 - 7.00	.84
Emotional	56	5.92	1.11	2.60 - 7.00	.71
Symptom	56	5.63	1.10	2.08 - 7.00	.91
Activity	56	5.49	1.19	2.82 - 7.00	.90

Results are expressed from 1 maximum impairment to 7 minimum impairment to quality of life.

Table 5

Comparison of Quality of Life Index - Respiratory Version Scores for Subjects Grouped by Gender.

	female (n = 32)			male (n = 22)			
QLI - RV (N = 54)	M	SD	range	M	SD	range	p value
Overall score	23.69	4.22	10.38 - 28.26	23.45	2.97	17.82 - 28.89	.82 [a]
Socioeconomic	24.29	5.22	7.21 - 30.00	23.86	3.31	16.50 - 29.64	.73 [a]
Psychological/ Spiritual	24.51	4.48	7.57 - 29.29	23.86	3.46	17.36 - 30.00	.57 [a]
Health & Functioning	22.99	4.62	13.63 - 29.43	22.74	3.95	14.65 - 28.13	.84 [a]
Family	25.43	5.68	8.00 - 30.00	25.59	3.86	15.00 - 30.00	.91 [a]

[a] equal variances

Table 6

Comparison of Asthma Quality of Life Questionnaire Scores for Subjects Grouped by Gender.

	female (n = 34)				male			
AQLQ Scale	M	SD	range	n	M	SD	range	p value
Overall score	5.71	.88	3.34 - 6.94	21	5.49	1.16	3.00 - 6.84	.43 [a]
Environmental	5.61	1.02	3.50 - 7.00	21	5.48	1.32	2.50 - 7.00	.67 [a]
Emotional	5.96	1.03	2.60 - 7.00	22	5.85	1.25	3.00 - 7.00	.72 [a]
Symptom	5.77	1.01	2.08 - 7.00	22	5.41	1.21	2.58 - 6.67	.23 [a]
Activity	5.56	1.17	2.91 - 7.00	22	5.38	1.23	2.82 - 7.00	.58 [a]

[a] equal variances

Table 7

Frequencies for Scores on the Asthma Severity Risk Index Total Scores for the Sample and Separated by Gender

ASRI Score Objective Asthma Severity	Total (N = 56)	Female (n = 34)	Male (n = 22)
1	4 (7 %)	3 (9 %)	1 (5 %)
2	32 (57 %)	18 (53 %)	14 (64 %)
3	11 (20 %)	7 (21 %)	4 (18 %)
4	3 (5 %)	3 (9 %)	-
5	3 (5 %)	-	3 (14 %)
6	1 (2 %)	1 (3 %)	-
8	1 (2 %)	1 (3 %)	-
17	1 (2 %)	1 (3 %)	-

Table 8

Frequencies for Coding Categories on Subjective Asthma Severity for the Sample and Separated by Gender

Subjective Asthma Severity	Sample (N = 56)	Female (n = 34)	Male (n = 22)
mild	27 (48 %)	17 (50 %)	10 (45 %)
moderate	23 (41 %)	14 (41 %)	9 (41 %)
severe	6 (11%)	3 (9 %)	3 (14 %)

Table 9

Summary of Low and High Objective and Subjective Asthma Severity Groups for the Sample and Separated by Gender

	Sample (N = 56)	Female (n = 34)	Male (n = 22)
Objective Asthma Severity			
low	36 (64 %)	21 (62 %)	15 (68 %)
high	20 (36 %)	13 (38 %)	7 (32 %)
Subjective Asthma Severity			
low	27 (48 %)	17 (50 %)	10 (46 %)
high	29 (52 %)	17 (50 %)	12 (55 %)

Table 10

Comparison of Quality of Life Index - Respiratory Version scores for Subjects Grouped by Objective Asthma Severity

	low asthma severity (n = 35)			high asthma severity (n = 19)			
QLI - RV Scale	M	SD	range	M	SD	range	p value
Overall score	23.68	4.16	10.38 - 28.89	23.44	2.87	17.58 - 28.26	.82 [a]
Socioeconomic	23.88	5.09	7.21 - 30.00	24.55	3.27	18.75 - 30.00	.60 [a]
Psychological/ Spiritual	24.12	4.59	7.57 - 30.00	24.47	2.99	18.64 - 29.14	.77 [a]
Health & Functioning	23.35	4.59	13.63 - 29.43	22.02	3.73	14.17 - 28.07	.28 [a]
Family	24.99	5.47	8.00 - 30.00	26.42	3.89	15.00 - 30.00	.32 [a]

[a] equal variances
* $p \leq .05$

Table 11

Comparison of Asthma Quality of Life Questionnaire scores for Subjects Grouped by Objective Asthma Severity

		low asthma severity			high asthma severity (n = 20)			
AQLQ Scale	n	M	SD	range	M	SD	range	p value
Overall score	35	5.81	.85	3.34 - 6.94	5.31	1.15	3.00 - 6.66	.10 [b]
Environmental	35	5.72	.96	3.50 - 7.00	5.28	1.35	2.50 - 7.00	.16 [a]
Emotional * †	36	6.18	.94	3.00 - 7.00	5.45	1.26	2.60 - 7.00	.02 [a]
Symptom	36	5.78	1.10	2.08 - 7.00	5.35	1.07	2.58 - 6.83	.16 [a]
Activity	36	5.65	.94	3.09 - 7.00	5.21	1.52	2.82 - 7.00	.25 [b]

[a] equal variances
[b] unequal variances
* $p \leq .05$
† clinical significance (difference ≥ .5)

Table 12

Comparison of Quality of Life Index - Respiratory Version Scores for Subjects Grouped by Subjective Asthma Severity

	low asthma severity (n = 26)			high asthma severity (n = 28)			
QLI - RV Scale	M	SD	range	M	SD	range	p value
Overall score * †	24.94	3.29	17.73 - 28.89	22.35	3.74	10.38 - 28.26	.01[a]
Socioeconomic	25.14	3.78	17.81 - 30.00	23.16	4.98	7.21 - 30.00	.11[a]
Psychological/ Spiritual	25.05	3.38	18.64 - 30.00	23.49	4.56	7.57 - 29.29	.16[a]
Health & Functioning * †	24.91	3.77	15.69 - 29.43	21.00	3.99	13.63 - 28.07	.00[a]
Family	25.62	4.03	16.50 - 30.00	25.39	5.80	8.0 - 30.00	.87[a]

[a] equal variances
* $p \leq .05$
† clinical significance (difference ≥ 2)

Table 13

Comparison of Asthma Quality of Life Questionnaire Scores for Subjects Grouped by Subjective Asthma Severity

	low asthma severity (n = 27)				high asthma severity			
AQLQ Scale	M	SD	range	n	M	SD	range	p value
Overall score * †	6.07	.58	4.78 - 6.94	28	5.19	1.11	3.00 - 6.53	.00[b]
Environmental * †	5.87	.85	3.50 - 7.00	28	5.26	1.30	2.50 - 7.00	.04[b]
Emotional * †	6.31	.67	4.40 - 7.00	29	5.56	1.31	2.60 - 7.00	.01[b]
Symptom * †	6.09	.70	4.42 - 7.00	29	5.19	1.23	2.08 - 7.00	.00[b]
Activity * †	6.02	.85	3.91 - 7.00	29	5.00	1.26	2.82 - 7.00	.00[b]

[b] unequal variances
* $p \leq .05$
† clinical significance (difference ≥ .5)

CHAPTER FIVE

Summary and Discussion

In this chapter, a summary of the significant findings in relation to each research question and other findings will be presented and compared to current literature. General limitations and recommendations for future research are addressed. Implications for nursing practice are found at the end of this chapter.

Asthma and Quality of Life

Question 1: What is the quality of life of adults with asthma who have been referred to a pulmonary specialist in a Canadian out-patient setting?

The results of this study indicate that the quality of life of adult asthmatics in this sample was high. The mean score of the sample on the overall QLI-RV and the overall AQLQ were in the upper quartile of the possible range of scores for each instrument. These findings are congruent with reports of other studies using samples of chronically ill adults. Using adapted versions of the QLI, the quality of life of cardiac disease patients (Arteaga & Windle, 1995; Daumer & Miller, 1992), patients with hemodialysis (Ferrans & Powers, 1985), and liver transplant patients (Hicks, Larson & Ferrans, 1992) were relatively high. Similarly, high mean scores on the AQLQ have been reported in studies of asthmatics with mild to moderate disease severity (Gibson, Talbot & Toneguzzi, 1992; Juniper, Johnston, et al. 1995).

The rank order of the mean scores on the domains within each of the quality of life measures are also congruent with previous work. Given that the domains for each instrument differ, each instrument is discussed separately.

The highest mean score on the QLI-RV for this group of asthmatics was found on the family domain. This indicates that subjects in this study had high satisfaction and placed a high importance on issues related to the health and happiness of their family members and their relationship with their spouse or significant other. The highest mean score on the family domain was also reported in other studies involving chronic illness groups (Anderson & Ferrans, 1997; Arteaga & Windle, 1995; Dalmer & Miller, 1992; Hick, Larson & Ferrans, 1992).

The lowest mean score on the QLI-RV for this group of asthmatic subjects was on the health and functioning domain. Subjects had a lower satisfaction with areas they identified as important such as their own health, the ability to breath without shortness of breath and the amount of energy they have for everyday activities. This domain was also found to have the lowest domain score for other chronic diseases including chronic fatigue syndrome and cardiac disease (Anderson & Ferrans, 1997; Arteaga & Windle, 1995; Dalmer & Miller, 1995). Of the four domains, it seems reasonable that the health and functioning domain would have the lowest mean score. The health and functioning domain examines the potential direct physical effects of respiratory disease on the individual.

The highest mean score on the AQLQ for this sample was found on the emotional domain. This suggests that individuals in this study rarely reported feelings of concern or frustration about having asthma, fear of not having asthma medication readily available or becoming short of breath. Malo and colleagues (1993) reported similar results on the emotional domain with a group of occupational asthmatics. For moderate to severe

asthmatics, the emotional domain was reported as the lowest mean score indicating the most impairment to quality of life (Apter et al. 1996; Gibson, Talbot & Toneguzzi, 1995).

The lowest mean score on the AQLQ in this study was on the activity domain. The five activities individually identified by the sample and overall limitation of those activities, including avoiding situations due to cigarette smoke, dust, weather pollution, perfumes or strong smells had the most impairment to their quality of life. This is similar to findings of asthmatics with occupational asthma (Malo et al., 1993). In contrast, the activity domain for severe asthmatics in two other studies was reported as the highest mean scores ($\underline{M}$ = 4.39 and $\underline{M}$ = 4.81)(Apter et al. 1996; Gibson, Talbot & Toneguzzi, 1995). These scores were still lower than the activity domain for this sample ($\underline{M}$ = 5.49).

Considering the four domains of the AQLQ, it is expected that feeling frustrated and concerned about having asthma would be less with individuals with well controlled asthma. The emotional domain focuses on feelings and fears about asthma and the availability of medications. The specific symptoms of asthma including chest heaviness, wheezing, difficulty breathing and not getting a good night's sleep are the focus in the symptom domain. It would not be expected that individuals with well controlled asthma would frequently experience these symptoms.

It is likely that relatively high scores on the quality of life measures indicate that these patients have adapted to their chronic illness. Alternatively, high quality of life scores may reflect the nature of the sample. Overall, the clinical characteristics of the sample are congruent with a well controlled mild category of asthma. To bear this out, further research is needed to compare the quality of life of newly diagnosed asthmatics

with those with similar disease severity and who have had asthma for longer periods. Longitudinal or cross-sectional studies with patients grouped by similar disease severity are needed to further examine the rank order of domains of quality of life. Closer examination of the domains could provide further information regarding the process of adaptation and how health care workers could assist in this process.

Gender and Quality of Life

Question 2: Are there differences between women and men with asthma and quality of life?

The results of this study failed to reject the null hypothesis. There were no clinical or statistical differences between gender on the overall or the domain scores on the QLI-RV or on the AQLQ. These findings were supported by the similar results using two different quality of life tools. Other researchers report similar findings using the generic QLI (Anderson & Ferrans, 1997; Hicks, Larsen and Ferrans, 1992) and the AQLQ (Malo et al., 1993). There were no differences between gender on the ranked order of the lowest and highest domain on the QLI-RV or the AQLQ.

It may be that gender differences on quality of life do not exist. The findings in this study and other reports support this conclusion. However, it may be that differences exist, but to date, differences have not been captured for two important methodological reasons. First, in this study and others, non-random sample techniques and small sample sizes were used (Anderson & Ferrans, 1997; Hicks, Larsen and Ferrans, 1992; Malo et al. 1993). Secondly, the instruments may be gender neutral.

To establish whether or not gender differences exist further research is warranted. Replication, using a more representative sample, is needed to reduce the possibility of type two error. In depth examination of the meaning of quality of life from the perspective of men and women using qualitative methods may help to determine if the current tools are gender neutral.

Objective Asthma Severity and Quality of Life

Question 3: Do asthmatics with low objective asthma severity compared to those with high objective asthma severity differ in quality of life?

The results of this study fail to reject the null hypothesis. The mean difference between low and high OAS on the overall QLI-RV and on the overall AQLQ were not statistically significant. There were no clinically or statistically significant differences between low and high OAS on any of the domains of the QLI-RV. The mean difference on the overall AQLQ was not statistically significant, but was clinically significant. The mean difference between low and high OAS on the emotional domain was clinically and statistically significant. Individuals with higher OAS had more feelings of concern about having asthma, getting out of breath, and the availability of their medications compared to those with low OAS.

The level of asthma severity has been shown to be negatively associated with quality of life using the AQLQ (Juniper, Guyatt, Ferrie & Griffith, 1993; Juniper, Johnson et al. 1995; Rowe and Oxman, 1993). The lack of statistical significance between low and high OAS on total scores and on the majority of domains in both instruments may be due to the lack of variance on ASRI scores. The scores on the ASRI were skewed.

Eighty-four percent of the sample had a score of three or less on the ASRI which has a potential score range of zero to 25. It may also be that the ASRI lacks precision in detecting differences in asthma severity. The significant differences between OAS on the emotional domain may be a spurious finding. Alternatively, of all of the domains used, the emotional domain may be more sensitive to differences on OAS.

Further research, with a larger sample of individuals representing a wider range of scores on the ASRI and using another objective asthma severity measure (e.g. FEV_1), may clarify the relationship between OAS and quality of life. To lend more precision to the ASRI, it could be further developed to include a disease history, dosage and frequency of various medications taken by the individual. These additions may be important factors related to disease severity that have implications when measuring quality of life. Cross-sectional or longitudinal studies using a more representative sample of asthmatics may clarify the relationship between the domains and measures of quality of life and OAS. Greater understanding of the relationships between the various domains and OAS may enlighten interventions related to asthma care.

Subjective Asthma Severity and Quality of Life

Question 4: Do asthmatics with low subjective asthma severity compared to those with high subjective asthma severity differ in quality of life?

The results of this study reject the null hypothesis. The mean difference between low and high SAS on the overall QLI-RV and on the health and functioning domain were clinically and statistically significant. The mean difference between low and high SAS on the overall AQLQ and on all domains were clinically and statistically significant.

Other published research studies comparing subjective disease severity and the quality of life of asthmatics could not be found. However, Rowe and Oxman (1993) found changes in the AQLQ total score was highly correlated with subject's assessment of physical changes one week following a visit to the ER ($r = .78$).

The significant differences between low and high SAS on both quality of life measures suggests that an individual's perception of their disease is positively associated with quality of life. Caution is advised in generalizing this finding beyond this sample due to two methodological issues. First, the non-random sample size limits generalizability. Secondly, the item used to measure subjective severity is of concern. The fixed options for responses of the item measuring subjective asthma severity are somewhat ambiguous. Subjects were asked "How would you rate the overall severity of your asthma condition?" Three fixed-alternative options were: severe (seriously interferes with normal lifestyle), moderate (occasionally interferes with normal lifestyle), and mild (infrequently interferes with normal lifestyle). The distinction between these definitions, particularly between mild and moderate are not clear. Furthermore, the definitions confine the subjects to considering the severity of their condition in terms of the impact on lifestyle.

Replication of this study with a larger, randomized sample is needed to corroborate these results. The single item would be clearer if the definitions were not provided and subjects were simply asked to choose between the three categories, mild moderate or severe. Further research on the relationships between the various domains and SAS may provide insight into interventions to increase the quality of life of asthmatics.

Other Findings

Psychometric Properties of the QLI-RV and the AQLQ

Internal validity was established for the overall QLI-RV and the overall AQLQ using Nunnally's (1978) criterion of .70. These results corroborate previous findings of high internal consistency for the QLI-RV (Anderson & Ferrans, 1997; Ferrans & Powers, 1985, 1992; Hicks, Larson & Ferrans, 1992) and for the AQLQ (Malo et al., 1993; Rowe & Oxman, 1993). The family domain of the QLI-RV had an alpha of .62 which was lower than alpha's reported for the family domain in the previously mentioned studies, but similar to a result of .66 for the QLI-cancer version (Belec, 1992).

The low alpha level for the family domain of the QLI-RV may suggest that there were an inadequate number of items in the domain to relate this item to measuring quality of life in the overall instrument (Brink & Wood, 1989). Beyond this study, the QLI-RV has not been utilized therefore, further research using this instrument is warranted.

The Relationship between the QLI-RV and the AQLQ

There was a weak relationship between the overall QLI-RV and the overall AQLQ. This adds evidence of convergent validity to the QLI-RV. This relationship is likely due to similarities between the health and functioning domain of the QLI-RV and the activity domain of the AQLQ.

The QLI-RV is based on a person's sense of well-being with important areas of their life (Ferrans & Powers, 1985), whereas, the AQLQ is specifically focused on how patients feel about and function with asthma (Juniper, 1995). These two tools have a different focus but both provide information on the quality of life of individuals with

asthma. Further research using the QLI-RV to compare subjects with asthma and other respiratory diseases (e.g. chronic obstructive pulmonary disease, cystic fibrosis, lung cancer) may provide increased knowledge about asthma and quality of life. Individual domains in each tool can also provide more information on asthma and quality of life.

The Relationship between ASRI and Subjective Asthma Severity

There was no relationship between the ASRI and subjective disease severity. When individual assignments to objective and subjective categories were compared, in the majority of cases the assignments were the same. However, there was a percentage of subjects for whom the objective and subjective categories differed. Caution is advised in terms of generalizing these findings, given the limitations of the measures as previously mentioned. Never the less these findings are similar to those of previous work. Nguyen, Wilson and German (1996) found a significant proportion of asthmatics accurately estimated their disease severity (54 %) while 20 % underestimated their disease severity, and 27 % overestimate their disease severity.

Individuals that underestimate their asthma severity may be at risk of increased mortality and those that overestimate their severity could be limiting their activity unnecessarily (Nguyen, Wilson & German, 1996). Further exploration of the relationship between objective and subjective asthma severity is warranted.

Implications for Nursing Research and Practice

Further nursing research is required to clarify the relationship between objective and subjective disease severity, gender and quality of life. Ideally, a larger sample, with random sampling techniques would enhance the ability to generalize these study findings

to a broader population. Although it may not be possible to obtain a probability sample, as the actual population of adult asthmatics is unknown, future studies could employ quota sampling techniques. Objective criteria such as FEV_1 measures could be used to divide asthmatics into different severity groups.

It is important for nurse researchers to realize that the concept of quality of life is subjective and multidimensional. How best to capture the subjective nature of quality of life has yet to be determined. The factors that contribute to the asthmatics quality of life are complex and as of yet not well understood. The two disease specific tools used in this study are complex and focus on different aspects of quality of life. One tool has not been found that captures all the important aspects of quality of life for an individual. Perhaps a single broad question measuring quality of life would be appropriate. What contributes to quality of life could then be explored on an individual basis. Qualitative methodologies may also help to capture gender differences and the subjective nature of quality of life.

It is equally important for nurses working at the bedside to recognize the need to assess an individual's quality of life. Nursing assessments should lead to the provision of appropriate and effective nursing interventions. Once the nurse has assessed the quality of life of an individual, exploration of what contributes and detracts from a higher quality of life can be explored. Nurses can then be involved in providing interventions that could help the individual adapt to their disease and potentially improve their quality of life.

Patient's perceptions of their asthma severity may play an important role in contributing to their quality of life. There is evidence to suggest that some patients may perceive their asthma to be either more or less severe than it is by objective measures of

asthma severity. These perceptions have the potential to affect not only physical functioning but also psychological aspects of quality of life. Nursing assessments of asthmatic patients should include information on the individual's perception of their asthma severity. It may be that in cases where there is an incongruency it is a result of misconceptions about asthma. Education, including the appropriate use of medications, lifestyle choices and awareness of symptoms can contribute to a better understanding of asthma. Accurate knowledge regarding the positive outcomes related to asthma may have an influence on an individual's quality of life.

The implications for nursing, described in the above paragraphs, emerged from a study of the quality of life of adult asthmatics and disease severity that was conducted during 1997 in Alberta. The improvement or deterioration in the quality of life of an individual has become an important outcome measure to consider when planning nursing research and patient care interventions.

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Appendix A

CONSENT FORM

Title : The Asthma-Anxiety Project

Researchers

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Purpose of the study

Some patients with asthma experience anxiety with their asthma symptoms. This is to be expected. Asthma symptoms can be frightening. For some people with asthma, anxiety can be problematic. The nurse researchers want to interview adults who have asthma. They will use the interviews to increase our understanding about normal and problematic anxiety in asthma patients. The results of this study will help us to improve our care of patients with asthma in the future.

Procedures

Being in this study involves about four hours of your time. You will:

(1) meet with a nurse researcher in an office in the Faculty of Nursing.

(2) the nurse will ask you questions about the following:
- Some personal information (example: age, marital status)
- your asthma symptoms.
- your asthma management
- the impact of asthma on your life
- your anxiety symptoms

(3) the nurse will ask you to complete five questionnaires related to asthma and anxiety symptoms.

Voluntary Participation

Being in this study is your choice. After the study is done, you will be given the chance to attend a small group patient-education program. We will base this patient-education program on the results of the study. We will design the patient-education program with the intent of helping you to better manage your symptoms.

Being in the study is risk free. If you need medical attention during the assessment, we will refer you to suitable medical services right away.

Even if you enter the study, you may refuse to answer any questions during the study. You may withdraw from the study anytime. You can withdraw by telling the nurse researchers of your wish (492-0784). Taking part in this study or dropping out will not affect your care.

We will keep information collected during the study in a locked cabinet for seven years. After seven years, the researcher will destroy this information. Only code number will appear on any form or question sheets. We will store consent forms separate from the questionnaires. We will keep all consents for at least five years.

We may use information collected in this study in future studies. We will get permission from the appropriate Ethics Review Committee before using it in other studies.

We may report findings from this study in published material or conferences. We will not use any information that may identify you in any report.

If you have any questions about this study later, you can contact the researchers by telephone (492-0784).

Consent

I agree to take part in this study. I understand the nurse-researchers will tell me the results of my interview assessment. I grant permission for the researchers to send an assessment report to Dr. _____(Specialist) and to Dr. _____ (General Practitioner), if necessary. I will receive a copy of this report.

The researchers have described the study to me. The researchers answered all my questions about the study to my satisfaction. I can contact the researchers (492-0784) if I have more questions. I understand the possible benefits and risks of joining the study. I understand the researchers will keep personal information about me confidential. I understand that I am free to drop out of the study whenever I wish without affecting my health care.

The researcher has given me a copy of this form to keep.

Signature _____Date_____ Signature: _____ Date_____
(Volunteer) (Researcher)

I also give permission for Dr. Ross to contact me in the future to be part of another nursing study. Yes ___ No ___

Signature _____Date_____ Signature: _____ Date_____
(Volunteer) (Researcher)

Appendix B

Demographic Form

Date: _____ Time Start:_____Time Complete: _____

(2) Subject's Age: _____

(3) Gender: 1 = female 2 = male

(4) Education (What is your highest level of education?)

1 grades 1 - 6
2 grades 7 - 11
3 granted high school diploma/ certificate or equivalent
4 completed some post secondary education courses toward degree/ certificate (technical, college, university)
5 granted post secondary (technical, college, university) degree/ certificate
6 completed some graduate courses Masters/ Doctorate

(5) What is your annual combined household income per annum (approximately)?

1 < $30,000
2 $ 31,000 - 40,000
3 $ 41,000 - 50,000
4 $ 51,000 - 60,000
5 $ 61,000 - 70,000
6 $ 71,000 - 80,000
7 $ 81,000 - 90,000
8 > $ 91, 000

(6) Marital Status

1 Married
2 Single
3 Widow
4 Divorce
5 Common Law
6 Other

(7) Who shares your living space (age of anyone described): _____

_____

(8) Asthma Severity Index Score _____

Appendix C

Asthma Questionnaire - Select Questions

1. How old were you when your asthma was diagnosed by a doctor?

2. Do you have any other illnesses ?

   - ☐ No (Go to question 3)
   - ☐ Yes (Please specify other illnesses)

_____

_____

_____

3. How would you rate the overall severity of your asthma condition?

   - ☐ Severe: seriously interferes with normal lifestyle
   - ☐ Moderate: occasionally interferes with normal lifestyle
   - ☐ Mild: interferes infrequently with normal lifestyle

4. In the last 12 months, did you need to go to the emergency room for your asthma?

   - ☐ No
   - ☐ Yes How many times? An estimate is OK _____

5. In the last 12 months did you need to increase your medication(s) to control your asthma?

   - ☐ No
   - ☐ Yes How many times? An estimate is OK _____

6. How often in the past two weeks did you wake up in the morning with asthma symptoms such as coughing, wheezing or chest tightness?

   - ☐ Not at all
   - ☐ 1 to 3 mornings
   - ☐ 4 to 8 mornings
   - ☐ 9 to 13 mornings
   - ☐ Every morning

7. How often in the past two weeks did you wake up at night to use your asthma medications?

- ☐ Not at all
- ☐ 1 to 3 nights
- ☐ 4 to 8 nights
- ☐ 9 to 13 nights
- ☐ Every night

8. Do you often feel that you have mucus or phlegm in your chest that needs to be coughed out?

- ☐ No
- ☐ Yes

9. Have you ever needed to take steroids such as Prednisone, Deltasone or Cortisone by mouth or injection? *This does not refer to inhaled steroids such as Beclovent or steroid creams.*

- ☐ No
- ☐ Yes

10. In the last 3 months, did you need a "short burst" or "short course" of steroids (less than 2 weeks) or if you are on regular steroid pills, did you need a dose increase?

- ☐ No
- ☐ Yes How often? ____Are you currently taking steroid pills? ☐ No ☐Yes

11. Are your asthma medications or treatments prescribed by any of the following. Check all that apply.

- ☐ Acupuncturist
- ☐ Allergist
- ☐ Chiropractor
- ☐ Emergency room doctor
- ☐ Family doctor
- ☐ Herbalist
- ☐ Naturopath
- ☐ Respiratory doctor
- ☐ Other _____

12. Have you ever needed to go to an emergency room to get help for your asthma?

- ☐ No
- ☐ Yes

13. Were you ever admitted to the hospital for a day or more for your asthma?

- ☐ No
- ☐ Yes how many times in the past year? _____
  were you admitted in the past 3 months? _____

14. Have you ever had artificial resuscitation such as mouth to mouth, cardiac massage (CPR) or insertion of a tube into the airway (intubation) for your asthma?

- ☐ No
- ☐ Yes

15. Please tell me which asthma medications or treatments you used in the last 2 weeks. How often did you take the medication and what is the specific name of the medication?

List of Medications and Treatments	How often taken in the last 2 weeks?	Name of Medication Please specify name & dose ordered
No Medication		
	☐ no medication taken in last 2 weeks	
Symptom Relief Medications		
beta2 bronchodilators: Alupent, Berotec, Bricanyl, Bronkaid, Medihaler, Nephron, Pro-Air, Salbutamol, Ventolin	☐ none ☐ occasionally ☐ every day	
ipratopium bronchodilator: (anticholinergic) Atropine	☐ none ☐ occasionally ☐ every day	
bronchodilator tablets containing theophylline: Choledyl, Phyllocontin, Quibron, Somophylline, Tedral, TheoDur, Theolair, Uniphyl	☐ none ☐ occasionally ☐ every day	

List of Medications and Treatments	How often taken in the last 2 weeks?	Name of Medication Please specify name & dose ordered
Preventative Medication		
inhaled steroids: Azmacort, Becloforte, Beclovent, Bronalide, Pulmicort, Vanceril	☐ none ☐ occasionally ☐ every day	
steroid tablets: Cortisone, Deltasone, Prednisone	☐ none ☐ occasionally ☐ every day	
inhaled cromoglycate/ nedocromil: Intal, Tilade	☐ none ☐ occasionally ☐ every day	
Zaditen tablets	☐ none ☐ occasionally ☐ every day	
allergy shots	☐ none ☐ occasionally ☐ every day	
herbal remedies	☐ none ☐ occasionally ☐ every day	
naturopath remedies	☐ none ☐ occasionally ☐ every day	
other	☐ none ☐ occasionally ☐ every day	

Appendix D

Quality of Life Index - Respiratory Version

Permission to use the Quality of Life Index - Respiratory Version was granted to Kathy Van Veen by Dr. Carol Estwing Ferrans.

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Ferrans and Powers
QUALITY OF LIFE INDEX©
RESPIRATORY VERSION

PART 1. For each of the following, please choose the answer that best describes how **satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. The health care you are receiving?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. Your ability to breathe without shortness of breath?	1	2	3	4	5	6
5. The amount of energy you have for everyday activities?	1	2	3	4	5	6
6. Your physical independence?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your potential to live a long time?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your relationship with your spouse/significant other?	1	2	3	4	5	6
13. Your sex life?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from others?	1	2	3	4	5	6

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HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to meet family responsibilities?	1	2	3	4	5	6
17. Your usefulness to others?	1	2	3	4	5	6
18. The amount of stress or worries in your life?	1	2	3	4	5	6
19. Your home?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. Your standard of living?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. Not having a job (if unemployed, retired or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Your financial independence?	1	2	3	4	5	6
26. Your leisure time activities?	1	2	3	4	5	6
27. Your ability to travel on vacations?	1	2	3	4	5	6
28. Your potential for a happy old age/retirement?	1	2	3	4	5	6
29. Your peace of mind?	1	2	3	4	5	6
30. Your faith in God?	1	2	3	4	5	6
31. Your achievement of personal goals?	1	2	3	4	5	6
32. Your happiness in general?	1	2	3	4	5	6
33. Your life in general?	1	2	3	4	5	6
34. Your personal appearance?	1	2	3	4	5	6
35. Yourself in general?	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes how **important** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Health care?	1	2	3	4	5	6
3. Being completely free of pain?	1	2	3	4	5	6
4. Being able to breathe without shortness of breath?	1	2	3	4	5	6
5. Having enough energy for everyday activities?	1	2	3	4	5	6
6. Your physical independence?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living a long time?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your relationship with your spouse/significant other?	1	2	3	4	5	6
13. Your sex life?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. Emotional support?	1	2	3	4	5	6
16. Meeting family responsibilities?	1	2	3	4	5	6

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HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
17. Being useful to others?	1	2	3	4	5	6
18. Having a reasonable amount of stress or worries?	1	2	3	4	5	6
19. Your home?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. A good standard of living?	1	2	3	4	5	6
22. Your job (if employed)?	1	2	3	4	5	6
23. To have a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Your financial independence?	1	2	3	4	5	6
26. Leisure time activities?	1	2	3	4	5	6
27. The ability to travel on vacations?	1	2	3	4	5	6
28. Having a happy old age/retirement?	1	2	3	4	5	6
29. Peace of mind?	1	2	3	4	5	6
30. Your faith in God?	1	2	3	4	5	6
31. Achieving your personal goals?	1	2	3	4	5	6
32. Happiness?	1	2	3	4	5	6
33. Being satisfied with life?	1	2	3	4	5	6
34. Your personal appearance?	1	2	3	4	5	6
35. Are you to yourself?	1	2	3	4	5	6

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Appendix E

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

SELF-ADMINISTERED

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FEBRUARY 1995

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

ACTIVITIES

We should like you to think of ways in which asthma limits your life. We are particularly interested in activities that you still do, but which are limited by your asthma. You may be limited because you do these activities less often, or less well, or because they are less enjoyable. These should be activities which you do frequently and which are important in your day-to-day life. These should also be activities that you intend to do regularly throughout the study.

Please think of all the activities which you have done during the last 2 weeks, in which you were limited as a result of your asthma.

Here is a list of activities in which some people with asthma are limited. We hope that this will help you to identify the 5 most important activities in which you have been limited by your asthma during the last 2 weeks.

1. BICYCLING	15. SHOVELLING SNOW
2. CLEANING SNOW OFF YOUR CAR	16. SINGING
3. DANCING	17. DOING REGULAR SOCIAL ACTIVITIES
4. DOING HOME MAINTENANCE	18. HAVING SEXUAL INTERCOURSE
5. DOING YOUR HOUSEWORK	19. SLEEPING
6. GARDENING	20. TALKING
7. HURRYING	21. RUNNING UPSTAIRS OR UPHILL
8. JOGGING OR EXERCISING OR RUNNING	22. VACUUMING
9. LAUGHING	23. VISITING FRIENDS OR RELATIVES
10. MOPPING OR SCRUBBING THE FLOOR	24. GOING FOR A WALK
11. MOWING THE LAWN	25. WALKING UPSTAIRS OR UPHILL
12. PLAYING WITH PETS	26. WOODWORK OR CARPENTRY
13. PLAYING WITH CHILDREN OR GRANDCHILDREN	27. CARRYING OUT YOUR ACTIVITIES AT WORK
14. PLAYING SPORTS	

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

Please write your 5 most important activities on the lines below and then tell us how much you have been limited by your asthma in each activity during the last 2 weeks by checking the box with the appropriate rating.

HOW LIMITED HAVE YOU BEEN DURING THE LAST 2 WEEKS IN THESE ACTIVITIES?

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited	Activity Not done
	1	2	3	4	5	6	7	9
1._____	☐	☐	☐	☐	☐	☐	☐	☐
2._____	☐	☐	☐	☐	☐	☐	☐	☐
3._____	☐	☐	☐	☐	☐	☐	☐	☐
4._____	☐	☐	☐	☐	☐	☐	☐	☐
5._____	☐	☐	☐	☐	☐	☐	☐	☐

HOW MUCH DISCOMFORT OR DISTRESS HAVE YOU FELT OVER THE LAST 2 WEEKS?

	A Very Great Deal	A Great Deal	A Good Deal	Moderate Amount	Some	Very Little	None
	1	2	3	4	5	6	7
6. How much discomfort or distress have you felt over the last 2 weeks as a result of CHEST TIGHTNESS?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
7. Feel CONCERNED ABOUT HAVING ASTHMA?	☐	☐	☐	☐	☐	☐	☐
8. Feel SHORT OF BREATH as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
9. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO CIGARETTE SMOKE?	☐	☐	☐	☐	☐	☐	☐
10. Experience a WHEEZE in your chest?	☐	☐	☐	☐	☐	☐	☐
11. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF CIGARETTE SMOKE?	☐	☐	☐	☐	☐	☐	☐

HOW MUCH DISCOMFORT OR DISTRESS HAVE YOUR FELT OVER THE LAST 2 WEEKS?

	A Very Great Deal	A Great Deal	A Good Deal	Moderate Amount	Some	Very Little	None
	1	2	3	4	5	6	7
12. How much discomfort or distress have you felt over the last 2 weeks as a result of COUGHING?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
13. Feel FRUSTRATED as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
14. Experience a feeling of CHEST HEAVINESS?	☐	☐	☐	☐	☐	☐	☐
15. Feel CONCERNED ABOUT THE NEED TO USE MEDICATION for your asthma?	☐	☐	☐	☐	☐	☐	☐
16. Feel the need to CLEAR YOUR THROAT?	☐	☐	☐	☐	☐	☐	☐
17. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO DUST?	☐	☐	☐	☐	☐	☐	☐
18. Experience DIFFICULTY BREATHING OUT as a result of your asthma?	☐	☐	☐	☐	☐	☐	☐
19. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF DUST?	☐	☐	☐	☐	☐	☐	☐
20. WAKE UP IN THE MORNING WITH ASTHMA SYMPTOMS?	☐	☐	☐	☐	☐	☐	☐
21. Feel AFRAID OF NOT HAVING YOUR ASTHMA MEDICATION AVAILABLE?	☐	☐	☐	☐	☐	☐	☐
22. Feel bothered by HEAVY BREATHING?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
23. Experience asthma symptoms as a RESULT OF THE WEATHER OR AIR POLLUTION OUTSIDE?	☐	☐	☐	☐	☐	☐	☐
24. Were you WOKEN AT NIGHT by your asthma?	☐	☐	☐	☐	☐	☐	☐
25. AVOID OR LIMIT GOING OUTSIDE BECAUSE OF THE WEATHER OR AIR POLLUTION?	☐	☐	☐	☐	☐	☐	☐
26. Experience asthma symptoms as a RESULT OF BEING EXPOSED TO STRONG SMELLS OR PERFUME?	☐	☐	☐	☐	☐	☐	☐
27. Feel AFRAID OF GETTING OUT OF BREATH?	☐	☐	☐	☐	☐	☐	☐
28. Feel you had to AVOID A SITUATION OR ENVIRONMENT BECAUSE OF STRONG SMELLS OR PERFUME?	☐	☐	☐	☐	☐	☐	☐
29. Has your asthma INTERFERED WITH GETTING A GOOD NIGHT'S SLEEP?	☐	☐	☐	☐	☐	☐	☐
30. Have a feeling of FIGHTING FOR AIR?	☐	☐	☐	☐	☐	☐	☐

ASTHMA QUALITY OF LIFE QUESTIONNAIRE PATIENT ID_____

SELF-ADMINISTERED DATE_____

HOW LIMITED HAVE YOU BEEN DURING THE LAST 2 WEEKS?

	Most Not Done		Several Not Done		Very Few Not Done		No Limitation
	1	2	3	4	5	6	7
31. Think of the OVERALL RANGE OF ACTIVITIES that you would have liked to have done during the last 2 weeks. How much has your range of activities been limited by your asthma?	☐	☐	☐	☐	☐	☐	☐

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited
	1	2	3	4	5	6	7
32. Overall, among ALL THE ACTIVITIES that you have done during the last 2 weeks, how limited have you been by your asthma?	☐	☐	☐	☐	☐	☐	☐

Appendix F

Asthma Severity Risk Index

		Points
Medication used now		
	Inhaled beta agonist	1
	Inhaled anticholingergic	1
	Theophylline	1
	Inhaled cromolyn	1
	Inhaled corticosteroid	1
	Prednisone required now	5
	Prednisone course within last 3 months but not taking it now	2
Morbidity		
	Hospitalization >1 within last year or within previous 3 months	5
	Previous intubation for asthma	10
Weighted Score	Total possible	25

Adapted from "Clinical markers of asthma severity and risk: Importance of subjective as well as objective factors" by S. Janson-Bjerklie, S. Ferketich, P. Benner & G. Becker (1992), Heart and Lung, 21(21), p.268.

Permission to use the Asthma Severity Risk Index was granted to Dr. Carolyn Ross by Susan Janson-Bjerklie.

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